Report to Congress and the Secretary by the Task Force

on

Technology Dependent Children

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FOSTERING HOME
AND
COMMUNITY-BASED CARE
FOR
TECHNOLOGY-DEPENDENT CHILDREN

Report of the Task Force
On Technology-Dependent Children

APRIL 7, 1988

REPORT TO CONGRESS
AND THE SECRETARY

by the
Task Force
on
Long-Term
Health Care Policies

U.S. Department of Heath and Human Services

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April 7, 1987

DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Care Financing Administration

Task Force on
Technology-Dependent Children

Room 4414 HHS Building
330 Independence Avenue, SW.
Washington, D.C. 20201
(202) 245-0070

The Honorable Otis R. Bowen, M.D.
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Secretary:

The Task Force on Technology-Dependent Children is pleased to submit this report on alternatives to institutional care for technology-dependent children. It was developed in accordance with Section 9520 of the Consolidated Omnibus Reconciliation Act of 1985 (P.L. 99-272).

As required by law, the Task Force conducted a comprehensive eighteen month examination of barriers that prevent the provision of appropriate care in a home or community setting. Also, it examined changes necessary in the provision and financing of health care in private and public health care programs to foster home and community-based alternatives to the institutionalization of technology-dependent children.

We addressed the issues that should be examined if the private and public sectors are to develop a coherent approach to technology-dependent children. The Task Force developed definitions for technology-dependent children, appropriate care, and case management which we believe makes a contribution toward defining a new direction for their care.

It is the goal of the Task Force to encourage action in the public and private sector to make appropriate care for technology-dependent children available in alternative community-based setting. We urge the private sector and public policy makers at the Federal, and State levels to proceed toward this goal.

On behalf of the members of the Task Force, I want to thank you for providing us with the opportunity to deliberate on technology-dependent children and to offer our recommendations to you and the Congress. We hope that the report will provide the guidance you need as you address these issues in the future.

Respectfully Submitted,

Robert G Kettrick MD

Robert Kettrick, M.D.
Chairman, Task Force on
Technology-Dependent Children

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

Task Force on
Technology-Dependent Children

Room 4414 HHS Building
330 Independence Avenue, SW.
Washington, D.C. 20201
(202) 245-0070

The Honorable Edward M. Kennedy
Chairman, Committee on Labor
and Human Resources
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

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(202) 245-0070

The Honorable John Dingell
Chairman, Committee on Energy
and Commerce
U.S. House of Representatives
Washington, D.C. 20515

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Chairman, Task Force on
Technology-Dependent Children

REPORT ON TECHNOLOGY-DEPENDENT CHILDREN

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TASK FORCE ON TECHNOLOGY-DEPENDENT CHILDREN

The Consolidated Omnibus Budget Reconciliation Act of 1985 (Public Law 99-272) required the establishment of a Task Force on Technology-Dependent Children to consist of representatives from Federal and State agencies with responsibilities relating to child health, private health insurers, providers of health care to technology-dependent children, large employers and parents of technology-dependent children. The Task Force was established by the Secretary of Health and Human Services, Dr. Otis T. Bowen, in October 1986. The members of the Task Force are:

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Special thanks go to Vince Hutchins, M.D., Director, Division of Maternal and Child Health, Public Health Service, Department of Health and Human Services who served as an active alternate member of the Task Force.

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I would like to sincerely thank the staff for their long hours and dedication in writing the report. The Staff and I also wish to express our appreciation to Miss Mary E. Donar, R.N. of Alfred I. DuPont Institute for her invaluable contribution. These very special children and their parents will be the beneficiaries of their efforts.

Wilhelm Pickens

ACKNOWLEDGEMENTS

The Task Force on Technology-Dependent Children and its staff would like to express its appreciation to the many people who contributed their efforts and time to make this report possible. We would especially like to thank the experts who made presentations to the Task Force and staff members of the Department of Health and Human Services who provided assistance, and in particular, the staff members of the Health Care Financing Administration who provided technical input, clerical support, and administrative assistance to overcome unique problems. The Task Force also expresses appreciation to Major Maureen Potter of OCHAMPUS, Judith L. Wagner and Elaine J. Powers of the Office of Technology Assessment, Congress of the United States, Patricia M. Pierce, Ph.D. Institute for Child Health Policy, University of Florida, Gainesville, Florida, Ed Feinberg, Ph.D. Psychologist and Program Coordinator, Anne Anrundel County Parent-Infant Program, Glen Burnie, Maryland and the many others who offered their assistance on request.

We have chosen not to use point-to-point citations in the text. Extensive citations of every major point would be required and undoubtedly some important contributions would be missed. We also felt that a major goal of producing this readable summary of themes would be better achieved without traditional research citations. To compensate for this approach, the bibliography will demonstrate the scope of our review. We hope this bibliography will serve as a useful resource for readers as well as an alternative to text citations.

Finally, the Task Force wishes to express gratitude to Otis R. Bowen, M.D., Secretary of the U.S. Department of Health and Human Services, and William L. Roper, M.D., Administrator of the Health Care Financing Administration, without whose personal interest and commitment, the resources to complete this report would not have been possible.

Charge to the Task Force

Section 9520 of the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) (P.L. 99-272) directed the Task Force to:

- Identify barriers that prevent the provision of appropriate care in a home or community setting to meet the special needs of technology-dependent children.
- Recommend changes in the provision and financing of health care in private and public health care programs, including appropriate joint public-private initiatives, in order to provide home and community-based alternatives to the institutionalization of technology-dependent children.

EXECUTIVE SUMMARY

REPORT OF THE TASK FORCE ON TECHNOLOGY-DEPENDENT CHILDREN

The Task Force on Technology-Dependent Children was given two major responsibilities by the Congress when the consolidated Omnibus Budget Reconciliation Act of 1985 (P.L. 99-272) was enacted. The first was to identify barriers that prevent the provision of appropriate care in a home or community setting to meet the special needs of technology-dependent children. The second was to recommend changes in the provision and financing of health care in private and public health care programs, including appropriate joint public-private initiatives, in order to provide home and community-based alternatives to the institutionalization of technology-dependent children.

In pursuit of these objectives, the Task Force defined a ''technology-dependent child'' as one who:

- Is a person from birth through 21 years of age (a person who has not reached their 22nd birthday);
- Has a chronic disability;
- Requires the routine use of a specific medical device to compensate for the loss of use of a life sustaining body function; and
- Requires daily, ongoing care or monitoring by trained personnel.

A second important definition developed by the Task Force that of ''appropriate care'' is the type and amount of specialized care required by the technology-dependent child to:

- Maintain life support,
- Provide an environment conducive to growth and development,
- Is documented and managed through the use of an individualized plan developed and monitored by a team which includes parents or guardians.

Because the Task Force was specifically asked to recommend changes in the provision and financing of health care, the report details three approaches for improving services to technology-dependent children and paying for those services.

Two of the approaches would provide comprehensive reforms in the provision and financing of services. The third approach recommends a series of incremental policy changes which make maximum use of the existing programs and expertise to redesign benefits to better finance care for technology-dependent children. Also during the consideration of these three approaches the Task Force emphasized its concerns over the growth in the cost of health care and the growth of the federal deficit, and viewed budget neutrality as an important element in providing cost-effective, and appropriate care to technology dependent children.

The service model outlined by the Task Force links financing to systems of excellence which are federally qualified and monitored but state certified and community-based. The concept calls for the providers and systems of excellence to deliver all medical, developmental, and support services for technology-dependent children for a flat fee. The providers of care and systems of excellence would be at-risk financially to stay within the amount negotiated with the payer for the care during a specified period of time.

Principal responsibility for the administration of the systems of excellence would be at the state level. The Department of Health and Human Services would develop broad criteria for state systems of excellence. States would be able to promulgate their own standards for the systems of excellence from the federal criteria. The major goal of the concept is the provision of comprehensive and coordinated care for technology-dependent children in the most cost-effective manner.

The Task Force found a number of barriers with respect to access to the financing of care for technology-dependent children. In calling for ''universal access'', the Task Force is not endorsing cost-free access to publicly-subsidized care for all technology-dependent children. The Task Force strongly supports preservation of the private sector's role as payer of first resort for the majority of children with an employed parent. In this regard, a combination of federal and state mandates and incentives to expand the number of privately insured families and to improve the adequacy of health insurance benefits is necessary and desirable. Private insurers must be prevented from terminating or reducing current commitments to technology-dependent children.

The primary goal of the Task Force for any system it recommends for technology-dependent children is universal access to family-centered, coordinated, community-based care, regardless of economic status, or physical condition. In formulating its recommendations, the Task Force agreed that its major proposals for financing appropriate care should have the following characteristics: (1) Universal access (2) Cost- efficient care (3) Family financial responsibility (4) Family participation in case management (5) Creative delivery of services to facilitate habilitative capability of the child (6) Public-private third-party cooperation (7) Assurance of high quality care (8) Expansion of service capacity on the local level. By reprioritizing and better coordination of existing medical services and financial resources many of the primary goals of the Task Force can be achieved without any increase in expenditures of federal revenues.

Some technology-dependent children have no private source of health care financing. For them, access to publicly-supported financing programs is critical. Publicly-financed third-party reimbursement needs to be broadened for families with expenses beyond a ''catastrophic'' proportion of their income. Eligibility for reimbursement should be based on family health-related out-of-pocket expenditures as well as upon traditional income and resource limits.

The Task Force Report proposes three approaches for the financing of care for technology-dependent children.

Financing Selected Incremental Policy Changes

This approach addresses elements in existing public and private health insurance policies and practices that limit opportunities for service in community settings. Unlike the two following approaches which would restructure the way services to technology-dependent children are organized and financed, this approach contains proposals to overcome some specific barriers to appropriate care in the design of current programs. The advantage of these recommendations for incremental change is that each can be carried out independently of the other to make the program more responsive to individual needs regardless of the outcome of other Task Force proposals for financing care. the major disadvantage is that adoption of separate recommendations will not assure that the principle of universal access to appropriate care for technology-dependent children will be achieved.

This approach identifies barriers, as requested of the Task Force by Congress, and makes a number of specific recommendations. These barriers and recommendations follow:

Barrier. Lack of universal access to financing for appropriate care for families with technology-dependent children.

Recommendations: (1) Congress should establish the principle of universal access to appropriate care for technology-dependent children. (2) Congress should require states to establish plans/timetables for achieving conformance with this principle.

Barrier. Insurance product benefit designs that are inadequate to meet the needs of technology-dependent children and insurance companies that are unresponsive to the needs of such families.

Recommendations: (1) Assuring that insurance rates are not excessive, discriminatory, or inadequate and are reasonably related to the actual costs of delivering benefits to the insured population. (2) Promoting the availability of full-benefit insurance products at discounted prices for low-income families. (3) Prohibiting waiting periods on pre-existing conditions that exceed six months. (4) Requiring health insurers to include case management services at no extra charge to families with technology-dependent children. In addition to all necessary medical and rehabilitative care, these services should include special services that permit cost-effective in-community and in-home care including respite care services and the availability and maintenance of primary and back-up durable medical equipment. Cost-effectiveness should be measured by comparison to the projected costs of acute care for technology-dependent children. (5) Encouraging insurers to offer structured settlements in the form of medical trusts for the care of technology-dependent children.

Barrier. (1) Health insurance policies that exclude coverage for maternal and prenatal care. (2) Insurance programs that exclude benefits for newborn infants. (3) Insurance benefit programs that do not include coverage for in-home care. (4) Inadequate benefits for durable medical equipment in health insurance policies.

Recommendations. Employers should offer and employees should seek health benefit programs which consist of at least the following benefit provisions for family coverage: (1) Maximum lifetime benefits of at least $1-million. (2) Maternal and prenatal care. (3) Coverage of children from birth. (4) Case management services. (5) In-home care. (6) Respite care. (7) Durable medical equipment.

Barriers. (1) Inadequate levels of support and coverage for technology-dependent children in state Medicaid programs. (2) Unavailability of Medicaid to some low-income families slightly above Medicaid income eligibility limits.

Recommendations. (1) Establishing a modest administrative capability to assist families with technology-dependent children to coordinate payment sources and to use available services effectively. (2) Identifying potentially eligible technology-dependent children so that they can be provided with targeted case management services. (3) Providing targeted case management services to coordinate appropriate care for families of all potentially eligible technology-dependent children, as authorized by the Consolidated Omnibus Budget Reconciliation Act of 1985.

Barrier. Inadequate commitment of states to maternal and prenatal care for low-income women.

Recommendations. States should expand their efforts to promote the birth of healthy babies through: (1) Extending Medicaid eligibility to pregnant women and to children up to age 22 when incomes are up to 200 percent of the federal poverty level. (2) Maximizing participation in the federal Maternal and Child Health program and the Women, Infants, and Children program and augmenting these programs with state-funded initiatives. (3) Undertaking programs to reduce teenage pregnancy.

Medicaid-Sponsored Financing Plan

The Task Force recommends that this Medicaid sponsored financing plan be considered as a first priority for implementation.

Under this approach, each state Mediciad agency through its Early and Periodic Screening, Diagnosis and Treatment (EPSDT) service authority and in consultation with its state Title V (Maternal and Child Health) program would arrange for the delivery by qualified systems of excellence of preauthorized medical, developmental, and support services specified in the individual care plan for a child certified as technology-dependent. The Medicaid agency would negotiate an individualized prepaid fee with the systems for coordination and delivery of a particular child's care over a defined period of time. This approach would make Medicaid administratively responsible for providing access to systematically coordinated care for all technology-dependent children without regard to their financial eligibility.

Medicaid was chosen because its preeminence in health care financing matters at the state level makes it difficult to consider creation of new programs outside its jurisdiction. This choice also assures a continued significant federal role in quality control. The EPSDT service authority was chosen to coordinate financing and services for technology-dependent children because it is already a mandatory service under each state's regular Medicaid program.

Medicaid would remain the payer of last resort under this approach. Even though Medicaid would pay for the services of systems of excellence on a prospective basis, the Medicaid agency would be authorized to assess and collect from each responsible third-party payer contributions up to the limits of that payer's liability for a particular child as well as reasonable contributions from the child's family.

Public-Private Consortium-Administered Financing

This approach was designed to both finance and coordinate delivery of services to technology-dependent children who have no private health insurance or who have exceeded their benefit limits under their private health plan or under public programs including Medicaid. The Task Force felt strongly that this approach should be addressed as a demonstration project, because of its financial risk and potential impact on public and private funds.

Development and administration of a care system for technology-dependent children without other coverage would be the responsibility of a consortium of private health insurance companies. Membership in the consortium would be determined through a bidding process conducted by the Department of Health and Human Services. The Department of HHS would also be responsible for assuring fiscal responsibility and providing quality assurance through Title V.

A technology-dependent child would be identified through state and local government procedures or by a hospital. When program eligibility is established, the consortium would price the risk, determine specific benefits, develop the provider network, and arrange for service delivery which utilizes a coordinated and case-managed approach.

Congress would establish financing by establishing a risk fund for the program with an initial endowment grant. Federal funds would also be required to subsidize the costly annual premiums paid by the children's families. This approach is modeled as a single-premium ''substandard'' major medical contract for a time certain (i.e. three years). Underwriting highly ''substandard'' (in this case generally uninsurable) risks is a new area for insurers. Such a contract is possible, but is considered highly risky without diminishing safeguards such as reinsurance.

This major medical contract would offer several advantages in financing the care of technology-dependent children. The carrier or consortium would receive payment on a prepaid basis for a time certain (i.e. three years) which would permit investment earnings and thereby reduce costs. The carrier or consortium would be responsible for paying the claims for the child's care and managing the child's care.

CHAMPUS

Recommendations for improving community-based services within the Civilian Health and Medical Program of the Uniformed Services include the following: (1) The Department of Defense should revise its policy of ''custodial care'' and increase the military health care system's flexibility in providing and financing family-centered, coordinated, care in the community for technology-dependent children. (2) Congress should raise the current $1,000 Program for the Handicapped (PFTH) limit for community-based services to remove current financial incentives for institutionalization. (3) Congress should change the regulation, policy, and operation of the PFTH to remove the current restriction of the dual use of the PFTH and the CHAMPUS Basic program. (4) In extending CHAMPUS' home care demonstration, Congress should broaden eligibility to include all technology-dependent children of military families meeting the Task Force's definition.

Other sections of the report deal with issues important to the delivery of appropriate care to technology-dependent children. Among the highlights are the following:

- Many of the barriers to home and community-based services for technology-dependent children are a by-product of the organization of federal and state governments and jurisdictional constraints.
- The unavailability or limited availability of services frequently complicates and hampers the provision of ''appropriate care'' to technology-dependent children. The Task Force has determined that access to appropriate home and community-based care for this population of children should be an entitlement based solely on identification of a child as technology-dependent.
- The Task Force heard repeatedly of variable quality and hazards in hospital discharge programs as well as home care programs for technology-dependent children. Services and quality vary tremendously from state-to-state and often within a state.
- The single most important aspect of ''appropriate care'' is case management. The Task Force recommends that Congress require states to develop and implement a program of comprehensive, community-based, family-centered case management to meet the special health, developmental, and educational needs of technology-dependent children.
- The most important variable in assuring appropriate development/educational services to technology-dependent children relates to the degree to which professionals, their agencies and the families can form an effective programming partnership. The debate about the provision and payment for services to this population centers on the fact that no agency has been given a clear mandate to provide these services.
- The Task Force defines ''family support'' as ''services, resources, information, training and emotional support that enables a family to assume responsibility and provide care for a technology-dependent child in addition to meeting goals and accomplishing tasks of family life.''
- Federal commitment to the prevention of chronic illness and disability is essential for all children and especially for technology-dependent children. This commitment should include public education, provision of preventive services to at-risk populations and continuing research on the efficacy of preventive intervention.
- Respite care was identified as a critical element in the provision of appropriate home care for technology-dependent children. As defined by the Task Force, ''respite care'' is a service for the family that provides an alternative to or substitute for family caregiving responsibilities of their technology-dependent child on a planned or unscheduled basis.
- Insufficient information exists on the design, staffing, and coordination of community-based and institutional programs to meet the individual needs of technology-dependent children. Significant gaps also exist in the collection of data in clinical and technological knowledge and standards, and in systematic efforts to assist families.

DEFINITIONS

The following definitions present the Task Force's interpretation of specific issues and terminology, including their understanding of what constitutes a ''technology-dependent child.'' A discussion of how these definitions were developed appears in Appendix A.

''A **technology-dependent child**:''

- Is a person from birth through 21 years of age (a person who has not reached his/her 22nd birthday); who
- Has a chronic disability; and
- Requires the routine use of a medical device to compensate for the loss of a life sustaining body function, (for example, dependence on mechanical ventilators or other device-based respiratory or nutritional support, including tracheostomy tube care, oxygen support, intravenous and enteral tube feeding); and
- Requires daily, ongoing care and/or monitoring by trained personnel.

''**Appropriate care**'' is the type and amount of specialized care required by technology-dependent children to:

- Maintain life support,
- Provide an environment conducive to growth and development, and
- Is documented and managed through the use of an individualized care plan developed and monitored by a team which includes parents or guardians.

''**Case management**'' is a process of care coordination which promotes the effective and efficient organization and utilization of medical, social, educational oand other resources to achieve or maintain the maximum potential of the child in the most appropriate, least restrictive enviornment. This process should be community-based and family centered, and directed through an individual (case-manager) for each technology-dependent child and family. (See Appendix A)

''**Individualized Care Plan**'' is a document which specifies achievable objectives or outcomes for the technology-dependent child, based on an assessment of the specific child's family's needs, and specifies the processes and resources necessary to achieve these objectives or outcomes.

CHAPTER I

INTRODUCTION

BACKGROUND

Over the past twenty-five years, advances in medical science have greatly altered expectations and outcomes of medical intervention. These advances have improved the medical community's ability to diagnose, treat and prevent disease and mitigate the impact of chronic illness.

Although the greatest improvement in reduction of childhood mortality and morbidity has been in the control of infectious disease, tremendous strides have also been made in the reduction of mortality rates from serious non-infectious childhood chronic illnesses. In the United States today, between 10 and 15 percent of all children suffer a chronic illness. Among these, 10 percent—about one million—have a severe chronic illness. This group includes children with such illnesses as cystic fibrosis, spina bifida, chronic kidney disease, hemophilia, mental disabilities, muscular dystrophy and other neuromuscular disorders.

Twenty-five years ago, most chronically ill children faced the probability of early death. Today, the survival of infants and children with conditions such as inborn errors of metabolism, neurological diseases, severe trauma and congenital abnormalities is increasing. The majority of chronically ill children survive into adulthood. Some of them do so through the advances in technology, equipment and medical management.

Tremendous advances in the care and survival of extremely premature infants (their death rate dropping by more than 55 percent since 1969) and in the survival of full-term low-birth weight infants have occurred in the last twenty years. In 1969, only half of all babies born weighing between 1,000 and 1,500 grams (3 lb., 4 ozs.) survived. Today, 85 percent of these babies and up to 25 percent of those weighing less than 750 grams (1 lb., 10 ozs.) survive, mainly through the utilization of technology, such as ventilators, and care delivered in highly specialized neonatal intensive care units.

Inherent in the use of technology to preserve life is the risk that some of these infants and children will never overcome their dependency on the intensive medical intervention and technology used to sustain life during acute illness. Some will suffer serious motor impairment, sensory loss and mental retardation. Others will remain dependent, in varying degrees, on life support devices such as ventilators, suction machines, hyperalimentation, and other devices which future developments may make available. These children are the focus of the Task Force's attention.

While long term dependence on expensive and sophisticated technology is not a new phenomenon, the current population of technology-dependent children is larger and more diverse than such populations in the past, for example, the polio survivors requiring respiratory support. Unfortunately the exact number of such children is unknown. Estimates of its size made recently by the Office of Technology Assessment (OTA) range from 2,300 to 17,000, depending on the level of technology needed.

The number of severely chronically ill children is expected to remain stable, at least for the next few decades. The same may not be true for those children identified as ''technology-dependent.'' This population is expected to increase in the future with changes and improvements in technology. A significant factor that could affect this trend is the projected increase in the incidence of pediatric Acquired Immune Deficiency Syndrome (AIDS), which grew about 30 percent for the six-month period from December, 1986 to June 1987. The number of AIDS cases of children and youths may continue to grow in the coming years and the degree of technology required for their care or treatment is uncertain at this time. (''Pediatric AIDS'' as defined by the Centers for Disease Control includes children from birth to 13 years of age.)

Concurrent with the need for medical life support devices is often the need for long-term skilled personnel support. Traditionally, care required by technology-dependent children has been provided in an acute care hospital at extremely high cost, both in terms of dollars and impact on the family structure.

In addition to the financial and familial costs, the cost to the growth and development of the child is substantial. Studies have shown that prolonged institutionalization poses significant problems in the overall health status, in family bonding and in the normal development and socialization of the child.

Creative approaches to care by physicians, improvements in miniaturization and portability of equipment and advances in delivery of home care services are expanding care options. This allows many technology-dependent children to receive needed medical and other supportive services at home.

There is little argument that without financial assistance, few families can support the specialized medical care and other services needed to maintain their technology-dependent child at home. Payment for non-hospital care is often difficult to obtain or is unobtainable. In addition, other barriers impede the movement of technology-dependent children from the institutional setting to home and community-based care. Identification of such barriers and recommendations to remove them was the focus of this Task Force's deliberations.

TASK FORCE APPROACH

The Task Force members are a diverse group which includes parents, professionals, third-party payers, service providers and federal and state policymakers who brought their own perspectives and experiences to the issues of providing care and services to medically fragile children.

The Task Force based its work on three principles:

- There should be equitable access to appropriate services for all children;
- The system of care should be family-centered, community-based, coordinated and comprehensive; and
- Services should be rendered in the least restrictive environment.

The Task Force gathered data by hearing public testimony and reviewing written testimony from numerous witnesses including families with technology-dependent children, third party payers including federal and state officials, providers and suppliers of services, experts in the field, disease-specific fund-raising and/or service organizations such as the March of Dimes and Cystic Fibrosis Foundation professional organizations, and provider and consumer associations.

The Task Force held 7 public meetings beginning in December of 1986. In order to provide opportunities for a wide range of witnesses to participate, meetings were held in Washington, D.C.; Los Angeles, California; Chicago, Illinois ; and Tampa, Florida. In addition, Task Force members and staff reviewed relevant technical documents and publications, met with staff of children's hospitals, visited homes of technology-dependent children, met with parents and attended conferences and meetings with special interest groups.

CHAPTER II

INITIATIVES

PUBLIC SECTOR

Much of the impetus for appropriate care for technology-dependent children has come from the public sector. A variety of activities have been directed toward meeting their needs. The Surgeon General's Workshop on ''Children with Handicaps and their Families'' in 1982 was held to:

- Develop strategies for comprehensive services needed by children with special health care needs;
- Address the challenges and burdens of these childrens' families; and
- Stimulate community resources.

The Workshop focused nationwide attention on ventilator-dependent children in particular, but the resulting concepts and recommendations have had important implications for children with other sophisticated technological needs and other serious, disabling chronic conditions.

Major Workshop recommendations for further activities included:

- Defining the scope of the problem;
- Developing model standards;
- Developing regionalized systems of care;
- Improving financing of care;
- Identifying areas of abuse;
- Incorporating principles of care into training for health professionals; and
- Supporting research.

The issues and recommendations emanating from this Workshop stimulated much of the current interest on the national level in home and community-based care for all chronically disabled children.

Several pilot programs funded by the Public Health Service, Bureau of Maternal and Child Health and Resources Development (BMCHRD) (formerly the Division of Maternal and Child Health) have contributed to overcoming barriers to placement of ventilator-dependent children in the most appropriate setting. Between 1983 and 1986, state Title V (of the Social Security Act) programs in Illinois, Louisiana, and Maryland received Special Projects of Regional and National Significance (SPRANS) grants to enable them to develop systems of comprehensive regionalized care for ventilator-dependent children. An independent evaluation of these grants, begun in late 1986, which is scheduled for completion in 1988.

Although each program is different, all take a multidisciplinary approach that facilitates both the discharge of technology-dependent children from hospital to home or alternative placement and coordination of the many services necessary to sustain the child in the community.

Experience with systems of regionalized care in these three states and in Iowa and Pennsylvania has encouraged replication of this approach in other States. As a result, a small but growing number of families have succeeded in bringing their technology-dependent children home.

In June 1987, Surgeon General C. Everett Koop, convened a Workshop on ''Children with Special Health Care Needs—Campaign '87.'' At this conference, he established a platform for a national agenda for family-centered, coordinated, community-based care. He challenged all health care financing agents, public, private and voluntary, to reexamine policies and make adjustments to assure appropriate coverage of chronically ill children. He also identified seven steps needed to improve access to care and the quality of life for all children with special health care needs. These seven steps involve:

- o Pledging a national commitment to all children with special health care needs and their families;
- o Encouraging building of community-based systems;
- o Assisting to ensure adequate preparation of care providers;
- o Developing coalitions to improve delivery of services;
- o Establishing guidelines to control costs of services;
- o Encouraging and supporting development of adequate health care financing; and
- o Continuing to conduct research and information dissemination.

Large cash assistance, health, social services, and education programs are nearly always jointly financed by the federal government and the states. Usually, the programs are directly administered by the states, with federal oversight. Sources of public funding for services to the technology-dependent children vary widely across states, as a function of state and regional economic pressures on state budgets. States have wide latitude within broad federal guidelines to design these programs to meet their own particular needs.

In addition to establishing or expanding indigent care programs, some states are considering new health care financing strategies for uninsured and underinsured children with long-term, high cost needs.

One strategy is high risk-pools which may be mandated by state law. A high-risk pool is an organization of insurers whose members share the financial risks associated with providing coverage to persons considered ''uninsurable.'' The purpose of state-mandated pools is to provide these individuals the opportunity to secure comprehensive health insurance coverage equivalent to that available under standard insurance policies. Nine states had high risk-pools in 1986. They are Connecticut, Florida, Indiana, Iowa, Minnesota, Montana, Nebraska, North Dakota, and Tennessee.

Five additional states have legislation on the books authorizing catastrophic health expense programs— Alaska, Maine, Minnesota, New York, and Rhode Island. In these programs, the state is the payer of last resort for persons who have incurred very high out-of-pocket medical expenses. Alaska, Maine and Minnesota had operational programs in 1986.

Recent estimates have placed the number of uninsured and underinsured disabled children who might benefit from these programs at about 60,000 for the high risk pool model and nearly 40,000 for the catastrophic health insurance model. Estimates for technology-dependent children are not available. Because of premium or deductible costs, both models are actually serving only a small proportion of the individuals eligible to participate. Most of those being served are middle-aged and elderly. The pools appear to be serving mostly moderate-income and middle-income families, while the catastrophic expense programs are primarily serving the poor. As enrollments have grown, expenditures have increased rapidly in both types of programs, leading some states to revise features of their original programs in order to control costs.

PRIVATE SECTOR

More than half of all children with major health problems were covered by some private health insurance plan by 1980. However, many of these plans do not provide coverage of catastrophic expenses associated with technology-dependent conditions.

Deductibles, copayments, and specific benefit limitations often severely restrict the utility of these benefits, especially for such services as mental health counselling, home health aide services, outpatient professional nursing services, durable medical equipment, and the spectrum of therapies. Exclusion from employer-based group policies as a result of pre-existing conditions and ineligibility for coverage due to loss of parental employment are also widely reported. The result is that the families of technology- dependent children are left with substantial and often devastating expenses.

Some recent trends in this area are encouraging. Escalating concerns about rising health care costs have led some employers to offer expanded and more flexible benefits for services which potentially reduce the need for hospital care. Many of these plans now include coverage of home care services including, occupational, speech, physical and respiratory therapies, as well as nursing.

A second positive trend has been the significant improvement in employer provisions for maximum lifetime benefits and out-of-pocket spending limits. In 1984, almost 40 percent of participants in medium and large employer health plans had either unlimited lifetime benefits or a $1 million lifetime maximum. Alternately, cost sharing, particularly major medical deductible requirements for employees, are increasing in most private health benefit plans. Thus, families of technology-dependent children can generally expect to have increasing out-of-pocket expenses for their children's care.

A number of large companies and some self-insuring businesses offer ''individual benefits management'' programs as part of their policies. Often implemented on a case-by-case basis, these programs offer the opportunity for coverage of services that are not part of the regular benefit package. For example, the coverage of home care services would be funded in lieu of in-patient hospital care more efficiently using available funds.

Blue Cross and Blue Shield, Kaiser Permanente and the military's CHAMPUS program have also begun pilot programs intended to improve service to children with special health care needs. These programs may extend special community-based health care benefits to targeted individuals and groups.

These efforts represent a source of assistance to families, but their current impact is still quite small. In a 1987 survey by a major benefits consulting firm, less than 20 percent of surveyed employer-based health care plans had incorporated individual benefits management into their overall benefit plans. Some children continue to be denied home nursing care, equipment and other necessary services, although these services may be substantially more cost-effective alternatives for a given child. In addition, individual benefits management programs do not eliminate problems that may accompany exhaustion of an insured individual's lifetime maximum benefits limit.

Few families are prepared to negotiate with insurance companies, health maintenance organizations (HMO's) or officials of public programs. As a result, obtaining access to needed benefits by securing coverage exceptions, is often difficult if not impossible.

CHAPTER III

NATIONAL CONCERNS

Establishment of the Task Force on Technology-Dependent Children followed several years of activity in the Administration and Congress to address issues related to the provision of appropriate health care services to children with special health needs. (See Legislative History) The issues before Congress have been:

- o Assuring services appropriate to enable disabled children to lead as normal a life as possible, in their schools and communities; and

- o Providing access and funding for home and community based services.

The desire of Congress to provide funds for appropriate non-institutional care has been restrained by pressures to contain spiraling health care costs, and slow the growth of the federal deficit.

The annual rate of growth of spending for health care services in this country has been in the double digits, 12.3 percent in 1970 and escalating to an all-time high of 15.7 percent in 1981. Health care's share of the gross national product grew from 6 percent in 1965 to 10.7 percent in 1985 and is estimated to reach 11.4 percent in 1987. During this same period, average per person annual health expenditures in this country have risen from $211 to $1,721. National expenditures for health care in 1965 were $41.9 billion compared to $425 billion in 1985 with estimates for 1987 reaching $525 billion.

Concern over the growth in the cost of health care, and in the growth of the federal deficit have resulted in concentrated efforts by both the Congress and the Administration to contain costs. The cost containment approach that currently typifies the budget process is ''budget neutrality,'' (i.e., health care benefits increased in one area are offset by cost-savings and program reform in other areas.)

Further, there exists a sense of caution on the part of public policymakers when making decisions to provide new benefits for specific populations because of what is commonly termed the ''woodwork effect,'' i.e., the concern that the known beneficiaries of a new benefit might only be a small portion of the total eligible population. No significant ''woodwork effect'' is likely for technology-dependent children meeting the Task Force's definition because the severity of their conditions makes it unlikely that they would be unknown to tertiary medical care facilities in their areas. However, there is no current national reporting system and the absolute number of technology-dependent children has not been determined. Although studies have begun to address these issues, the numbers may remain unreliable because of the varying definitions of technology-dependent children and data collection limitations.

To date, there has been no widely accepted agreement on the definition of ''technology-dependent,'' or on the size of the technology-dependent population. Further, there is no consensus on a definition of appropriate services; or where those services are being provided. Despite the presence of several successful demonstration programs, there has been no solid demonstration of cost-effectiveness of appropriate care in varying locations. The Office of Technology Assessment report provides the most recent and comprehensive information and reflects continuing Congressional and Administration interest.

There are compelling reasons for making resources available now to between 2,300 and 17,000 children who meet this Task Force's definition of technology-dependent. We know a great deal about the needs of technology-dependent children. It is clear that a lack of early intervention and case management can have a disastrous impact on outcome and that early intervention can help to mitigate this. The catastrophic nature and the sheer volume and variety of costly services which technology-dependent children need makes it reasonable to offer all families access to systematically organized financing and care, regardless of income. There is no single recipe for services which can be uniformly applied to all technology-dependent children, and care plans must be customized to meet each child's specific developmental, as well as clinical needs. Carefully implemented and evaluated demonstration projects have shown that efficient, high quality programs can be developed to serve these children successfully in their own homes and communities.

CHAPTER IV
GOVERNMENTAL

INTRODUCTION

Americans are generous in their attitudes of support for the underprivileged and the handicapped. However, the structure of government and competition for resources often frustrates the transformation of attitudes, knowledge, and expertise into workable policies and programs. In addition, multiple federal, state, and local jurisdictional boundaries frustrate the transformation of useful health, human services, and educational policies and programs into a coherent, unified system. Many of the barriers to home and community-based services for technology-dependent children are a by-product of the organization of federal and state governments and jurisdictional constraints inherent in this governmental organization.

This Chapter will identify a number of governmental barriers — both policy and jurisdictional — to family-centered, coordinated, community-based care for technology-dependent children and offer recommendations for overcoming them.

POLICY DEVELOPMENT

BARRIERS

- There is no broad-based constituency with an understanding of and commitment to resolution of problems facing technology-dependent children and their families.
- Finite financial resources available for federal, state, and local programs promote competition among deserving groups for priority.
- The governmental process, current budget deficit, and competing health agendas limit the possibilities for new spending at federal and state levels.
- Historically, costs for health care programs have been underestimated, creating skepticism with regard to estimates for new programs.
- Congress prefers to preserve states' flexibility, thereby perpetuating variability in existing federal-state health benefit programs. This variability frequently means inequity in service provision and in access to home care.

- Biases toward institutional care settings, reflected in regulatory restrictions, in some federally-financed programs, limit or prevent eligibility for home and community-based services for children for whom such care is medically appropriate.

DISCUSSION

Meeting the needs of technology-dependent children brings into focus the overall question of the nation's commitment to the use of available national resources to meet the health care needs of children. The Task Force recognizes that competition for scarce resources is central to the establishment of public policy. The priority assigned to any issue or group within the political process is reflected in the willingness of elected officials to provide funding. Decisions concerning such funding generally involve balancing the the competing interests of different groups. For example, advocates for children with chronic illnesses must compete with advocates for the elderly and adult disabled population. In an aging society, the interests of the elderly can be expected to hold their own in any generational competition for new health care benefits.

Given the realities of competition for available resources, it is clear that program cost will remain important in determining national resource allocation for technology-dependent children. Despite evidence of the efficiency of coordinated, community-based care for technology-dependent children, reluctance exists at state and federal levels to authorize new spending. Therefore, no matter how worthy the purpose, proposals for restructuring health benefits that will increase overall spending have little chance of enactment.

Elected officials, health policy architects, and administrators fear the ''woodwork effect,'' i.e., simply providing a new benefit brings additional and unanticipated people forward to use it. Previous experience with the Medicare renal dialysis program and its enormous unanticipated cost, for example, serves as a constant reminder to legislators and policymakers of how this phenomenom can escalate costs beyond those projected. Outcomes such as this have made lawmakers skeptical about amending major health reimbursement programs for limited populations and have reinforced resistance to new entitlements. The Task Force is concerned that fear of a ''woodwork effect'' has created a reluctance to aggressively pursue resolution of the problems of technology-dependent children and their families. This fear is insufficient reason to delay action on legislative relief for these children and their families. Rather, it is a reason to proceed with carefully crafted definitions, policies, and programs.

Adding to the sense of caution that underlies current political approaches to addressing health care financing issues is the fact that responsibility for health and social support services has only recently been recognized as a possible third-party obligation. The absence of a third-party tradition of payment for community-based services in addition to their potential high cost contributes to lack of a clear-cut policy commitment to the achievement of appropriate long term care for chronically ill children. The degree to which public as well as private health insurance has been available for community-based support services necessary for the child to remain outside of institutions continues to be subject to comparisons of ''cost-effectiveness'' and approved by payers only on a case-by-case basis.

Public and private reimbursement policies and practices have fallen far behind advances in medical care and organizational innovations that have made it increasingly realistic to extend into noninsitutional settings and under family supervision, treatments that even a short time ago were unthinkable outside acute care settings. The magnitude of Medicaid's institutional care investment and limited funds have delayed federal and state Medicaid agencies from reassessing issues vital to the future of community-based care. Continued use of such terms as ''homebound'' or ''custodial'' by federal, state and private payers to differentiate patients and conditions for reimbursement should be reevaluated. Health professionals find these terms arbitrary and irrelevant when applied to infants and children. Yet, terms such as these and distinctions based on the medical setting or ''level-of-care'' in which care is rendered, are regularly used to reduce or deny payments for care in the community.

Congress' preference for state flexibility and autonomy has perpetuated extreme variability in existing federal-state health benefit programs for children. This has produced a pattern of inequity of services for children from state-to-state.

If program and policy changes affecting technology- dependent children are to be achieved, advocates must give special emphasis to raising public awareness of these children and the special issues affecting their care. Insufficient public awareness of problems facing technology-dependent children impedes creation of positive public sentiment. Unlike organ transplant appeals, which have received regular mass media attention, issues involving technology-dependent children are only beginning to receive the local and national attention that helps to stir governmental action.

RECOMMENDATIONS

- **Public and private advocates for community-based care must be encouraged to develop and implement strategies to increase public awareness of special issues affecting children's health. Task Forces, special study commissions, parents, and special interest groups should target elected officials and the media for awareness campaigns relative to the care of technology-dependent children.**

- **Congress should develop and implement legislative strategies for ensuring access to programs that meet the individual needs of technology-dependent children.**

- **Congress should develop legislative strategies requiring all public and private payers that finance health care for technology-dependent children (including health benefit programs for federal civilian and military personnel) to develop appropriate measures for ending institutional bias within these programs.**

JURISDICTIONAL

BARRIERS

- Inconsistencies, inequities, gaps, and conflicts among multiple programs, agencies, and levels of government exist in systems delivering care to technology-dependent children.

- The jumble of federal and state legislative committees and agencies with jurisdiction over issues involving technology-dependent children makes simple solutions difficult to achieve.

- No solution to the problems involved in making home-based care available to technology-dependent children can be achieved without the cooperation and coordination of the federal government, states, insurers, providers, and families.

- There is an absence of mechanisms to improve cooperative linkages and organizational interrelationships among policymakers in key programs serving technology-dependent children, including Title V, Medicaid, special education for the handicapped, and other related programs.

- States have limited capacity for effective regulation of private employer-based health benefit programs.

- States have variable commitments to publicize availability of programs that can assist in financing and providing services for technology-dependent children.

DISCUSSION

In 1986, the National Council on the Handicapped published a listing of major federal disability programs, including the organizational and legislative authorities charged with their oversight. The listing identified 49 separate programs, most serving both children and adults. These programs are administered by eight sub-agencies within five different Cabinet departments, by an additional six independent executive agencies, and by one joint Executive-Congressional unit. Eight Committees of the House of Representatives, six Senate Committees, and one joint House-Senate Committee exercise jurisdiction over one or more of these programs.

The existence of multiple programs dealing with federal disability policy and the dissipation of administrative authority and Congressional oversight over so broad an array of agencies is, itself, the most serious governmental barrier to community-based care for technology-dependent children.

No single entity within the Congress or the Executive branch now has broad enough jurisdiction or enforcement powers to mandate the consistent coordination of all public programs serving disabled children's health, education, and welfare needs.

States have great latitude within the largest federally-funded programs affecting child health — Medicaid and Title V — to adapt them to their own needs. This flexibility enhances states' freedom to set priorities, but contributes enormously to what President Reagan has called "the patchwork quilt of existing policies and programs."

Variability and complexity are further compounded because some policies and programs affecting important needs of technology-dependent children are not subject to direct federal control. For example, operation of public school systems and regulation of the commercial insurance industry are primarily state concerns. In addition, states are limited in their ability to assure participation by all private sector payers in cooperative efforts needed to close key coverage gaps in public and private programs because important segments, such as health maintenance organizations (HMO's) and self-insured programs, are governed by federal law, beyond state regulatory control. States' limited ability to assure even minimal uniformity in private insurance coverage offers private industry little incentive to cover the costly conditions that lead to technology-dependency.

From the perspective of consumers, the often conflicting requirements of this mass of programs, agencies, state programs, and legislative committees can be overwhelming. Administratively, the absence of mechanisms to reconcile inconsistent policies of different government agencies encourages duplication of effort and discourages efficient service delivery, thus leading to higher costs.

Failure of the Title V and Medicaid programs to mesh, in spite of existing legislative mandates for cooperation, is a severe challenge to efforts to construct appropriate care plans for technology-dependent children. These two programs provide most of the public financing of patient care and support services for these children. Enacted as part of the original Social Security Act, Title V has traditionally sponsored extensive services to children with special health care needs (formerly designated ''crippled children's'' services). The original program has expanded over time from a concentration on conditions such as polio and cerebral palsy to enable states to serve children with a greater variety of chronic illnesses. The program is operated under state Maternal and Child Health block grants and through grants for Special Projects of Regional and National Significance (SPRANS).

Since 1982, Title V Administrators have actively promoted expansion of community-based services for ventilator-dependent children. They play a significant advocacy role for family-centered, coordinated, community-based care for technology-dependent children. Despite expertise in care coordination and in building service capacity, however, Title V's influence is overshadowed by Title XIX. Its total child health expenditures ($457.5 million in 1986) are dwarfed by those of Medicaid, which has become the single most important influence on the health care of low-income women and children. Medicaid expenditures for individuals under 21 years old amounted to over $6 billion in 1986.

Yet the Task Force repeatedly heard that the expanded access to basic health services provided by Medicaid has not assured availability of specialized services for children with complex health care needs. This is largely because there is little programmatic consistency in either Title V or Medicaid programs across the states, and little integration or coordination between them. States enjoy wide latitude in setting their own requirements for eligibility, amount, duration, scope of services, payment mechanisms, and reimbursement limits.

Witnesses before the Task Force almost unanimously agreed that Title V's traditions, philosophy, and accomplishments qualify it to play a leading role in designing, coordinating, and monitoring any program of Medicaid-financed community-based care for technology-dependent children. It is clear from recent experience that extensive interaction between Medicaid and Title V in administration of Section 2176 waivers is already occurring in a number of states, with favorable results. In these states, Title V agencies are managing waiver programs targeted to technology-dependent children under inter-agency agreements with the state Medicaid agencies. A recent nine-state survey of waiver programs serving disabled children confirms that a strong Title V presence in the operation of a state's waiver program is strongly associated with an emphasis on quality assurance.

The cooperation displayed by some state Title V and Medicaid agencies with respect to waiver programs surfaces less often in Medicaid's only direct child-oriented service program. The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program is one of Medicaid's few mandatory services. It requires all state Medicaid agencies to pay for screening and diagnostic services to determine physical and mental defects in Medicaid recipients under 21; and health care, treatment, and other measures to correct or ameliorate any defects or chronic conditions discovered.

Title V agencies represent a source of innovative practices, standards, and services needed by EPSDT programs, such as outreach, screening, diagnosis and treatment, health education, counseling, and case management. But only a few state EPSDT programs now take advantage of available Title V expertise.

Without major legislative change, EPSDT could offer states a means of targeting individualized care to children with extraordinary service needs without reliance on waivers. Most states, however, do not provide EPSDT services beyond the limited scope required in Federal regulations.

The Task Force is encouraged by evidence of current informal actions to remove existing jurisdictional and organizational barriers to community-based care for children. For example, both the Medicaid and Title V State Directors' Associations have recently established a technical advisory group devoted to exchanging views on how to maximize human and dollar resources and reduce duplication between EPSDT and MCH block grant activities. Development of these informal links can pave the way for future staff and policy-level communication and consultation.

In the daily business of government, however complex coordination issues that require sustained, concerted action with little immediate gain are likely to receive little attention. There is an inportant need for more formalities among all publicly-financed services programs for technology-dependent children. Opportunities for coordination can result from a wide range of regular interactions amoung policymakers and program developers.

The frustration and insecurity engendered by a lack of ''system'' and the conflicting requirements of current programs used to serve technology-dependent children were recurrent themes in testimony to the Task Force. Families, professionals, and policymakers agreed that too often the service delivery system fails to ''deliver.'' Complex regulations, age restrictions, program inflexibility, massive paperwork, interagency disagreements, service delays and unpublicized program options are only a few of the barriers that have hampered a child's release from institutional care. HCFA's Medicaid waiver approval process and CHAMPUS's regulatory restrictions against ''custodial care'' have been regarded by parents as particularly difficult.

The variety and complexity of complaints against current programs makes it evident that no single solution exists to the need for better coordinated services. The Task Force believes that mechanisms should be in place throughout the service delivery system to improve linkages among policymakers and programs serving technology-dependent children. Such mechanisms should encourage productive interaction by all parties involved in policy decisions affecting technology-dependent children. Clarification and harmonious integration of the roles and policies of Title V, Medicaid, CHAMPUS, developmental disabilities, special education, rehabilitation and other key service providers is a minimum objective of an improved service delivery system. The process must involve state and local policymakers, private organizations, the Congress and the Administration.

In addition to national level activities, state and local planning by federally-funded programs should be initiated in every community. For example, a state planning requirement similar to the one now in place for citizens with developmental disabilities would address the specific needs of technology-dependent children at state and local levels. The planning process would seek participation by existing health and education agencies in each state and community. Case managers, providers, suppliers, insurers, facility administrators, and universities would also be represented in this consortium. Families would, by requirement and design, be substantially involved in the planning process.

One specific objective of the state planning process would be to identify methods to improve service delivery, with particular attention to the needs of these children for interdisciplinary planning and cooperation. A second objective of the planning process would be development of mechanisms to avoid the dislocating effects on children of service interruptions. These interruptions are often caused by exhaustion of previous sources of financing prior to eligibility for public funding. A final objective is emergency preparedness planning with police, fire departments, and power companies.

The Task Force believes that, in states and local communities, a unified planning effort will lead to improved communications, more integrated services and better informed consideration of policy options. If implemented in good faith at the state and local levels, this planning recommendation can lead to substantially improved service efficiency. It can result in a federal, state, local and private sector partnership to provide effectively coordinated, non-duplicated services that enhance opportunities for technology-dependent children.

Recommendations

- **Congress should establish a process for integrating conflicting federal legislation and overlapping jurisdictional boundaries that reduce the effectiveness of federally-financed health care programs in providing community-based health care for technology-dependent children.**

- **Congress should develop legislation to facilitate the development of more comprehensive private employer-based health benefit programs which could provide and coordinate benefits for technology-dependent children.**

- **Congress and HHS should strengthen the authority of the Bureau of Maternal and Child Health and Resources Development (BMCHRD) and state Title V agencies respectively, to assume leadership for the provision of comprehensive care for technology-dependent children in the least restrictive environment in areas of special strength, including standard setting and monitoring; developing innovative services; and building local service capacity.**

- **Congress and HHS should assure that mechanisms are in place to improve linkages and define appropriate relationships among Title V, Title XIX, and other federal policymakers and programs serving technology-dependent children.**

- **Congress should require state and local governments and public and private agencies receiving federal funds for services for technology-dependent children to participate in development of coordinated service delivery plans.**

- **Family and child advocates should aggressively pursue existing opportunities to participate in developing, modifying, and approving federal regulations and guidelines governing health and social service programs for children.**

CHAPTER V

ACCESS

INTRODUCTION

The unavailability or limited availability of services frequently complicates and hampers the provision of appropriate care to technology-dependent children. The Task Force has determined that access to appropriate home and community-based care for this population of children should be an entitlement based solely on identification of a child as technology-dependent. This chapter deals with issues related to the availability of alternative care settings and the ability of professionals to provide care in the community. Access issues related to funding are addressed in Chapter XIII: Financing.

BARRIERS

- Limited availability of alternatives to acute hospital care or home care i.e., transitional facilities, foster homes, specialized adoption, supervised apartments, group homes and pediatric skilled nursing facilities.
- Lack of appropriately trained physicians to provide services.
- Shortage of registered nurses nationwide.
- Shortage of registered nurses qualified to provide home care, supervision and case management for technology-dependent children.
- Rapid turnover of home health agency nursing staff.
- Shortage or unavailability of home health agencies in rural areas to provide nursing care.
- Lack of training programs relative to care of technology-dependent children, case management and family support.

DISCUSSION

Technology-dependent children belong in the community, in the ''least restrictive environment'' appropriate for their growth and development. In most cases, the most appropriate environment for a child is in their home, with community support and services for the family. Community support and services should focus on the needs of the family and include providing the child and family with access to a continuum of care. That continuum should include acute care hospitals, transitional facilities and/or stepdown units within hospitals (a level of care below acute hospital care but which requires intensive skilled nursing care), rehabilitation facilities, pediatric nursing homes, small group homes, foster care, specialized adoption, respite care and medical day care. Availability of these options for families able to provide care for their child at home may avoid prolonged stays in acute care institutions. For families unable to care for their child at home, these options for care and integration into the community are critical. These options should be available for families of technology dependent children.

VIEW OF THE CURRENT SERVICE SYSTEM

Many components of existing service systems were established to serve mentally retarded and other developmentally disabled populations. The guiding principle in providing services to persons with disabilities, for the past 15 years, has been the concept of ''least restrictive environment.'' The census of public institutions for the mentally retarded and developmentally disabled, estimated at 194,550 in 1967, has steadily declined, to about half that number, since the late 1960's. For severely disabled persons, placement in the ''least restrictive environment'' has often been transfer from large public institutions to smaller intermediate care facilities for the mentally retarded, or private institutions.

Development of group homes, independent living efforts and foster care programs for this group has been slow. Many professionals and policy makers may incorrectly still believe that severely disabled persons are unable to function in more normalized settings. This evolution has also been influenced by a pattern of state and federal funding which has favored institutional placement. For example, the major federal program designed to serve the developmentally disabled, the Intermediate Care Facility for the Mentally Retarded program, requires placement in an institution and community-based care has been severely limited.

Patterns of service provision are changing, however, as a result of efforts by parents, advocates, and disabled persons and as innovative community programs are sucessfully integrating the most severely disabled persons into the community. The state of the art in serving the developmentally disabled person is moving toward a more individualized, integrated and responsive system for providing services. This trend is expected to continue as increasing numbers of individuals with severe developmental and physical disabilities are receiving care and services in the community, in independent living arrangements, supervised apartments, group homes and in specialized foster care.

While some technology-dependent children may also be developmentally disabled, their need for sophisticated life support services are beyond the traditional service capabilities of programs for the developmentally disabled child. Therefore, technology-dependent children are often under served, inappropriately served, or not served in service systems designed for the developmentally disabled child. Many technology-dependent children reside in acute care facilities or institutions for the developmentally disabled due to the lack of available financial and/or support services for home care, or because home care or other care alternatives do not exist.

ACCESS TO ALTERNATIVES

Discharge from the acute care hospital depends on the availability and flexibility of alternatives in the community. Because the population of technology dependent children is relatively small, efforts to assure access to community-based services are usually not part of long range state and/or community planning. In the arena of specialized foster care for example, most programs do not provide placement for medically fragile and/or technology-dependent children.

Where these children are placed in foster care, good public service systems offer a wealth of support to foster parents including respite care, home health aide, nursing and other services. These service systems have traditionally not supported the birth family in the care of their family member at home. As a rule, birth families have and continue to bear the full responsibility for care without the services and supports they need. Public policymakers are, however, beginning to recognize the benefits of supporting birth families that choose to provide care for their family member at home.

The discharge of some technology-dependent children from the acute care hospital is seriously hampered by the lack of facilities below the acute care level willing and able to provide transitional and/or ongoing care. A recent survey on the numbers of children in the Los Angeles area residing in tertiary care hospitals identified 71 children, representing 747 patient days, who could benefit from a transitional care facility. The State of California is designing a demonstration project to develop a ''transitional care facility'' to move medically stable children from acute care facilities into transitional settings where service delivery will focus on teaching caregivers and further rehabilitation of the child in preparation for the child's discharge to home.

Group homes for technology-dependent children are generally unavailable. Ventilator-dependent children are often excluded from admission to those that do exist. The State of California recently recognized this service gap with legislation creating a new category of residential living for the mentally alert, physically dependent adults and children. These independent living arrangements will serve no more than six individuals in each residence. Full implementation of this program is expected to take about a year.

There is a need for day care programs for severely compromised infants. Recently enacted legislation by the State of Florida creating a licencing category for pediatric day care —''Prescribed Pediatric Extended Care'' (PPEC)— expedites the development of such programs within that state and could serve as a model for other states. This legislation evolved from a model PPEC facility developed under a Special Projects of Regional and National Significance (SPRANS) grant in Tampa, Florida. The PPEC is an innovative alternative in the continuum of care, offering an array of services focusing on children's physiological, developmental, physical, nutritional and social needs. Under the Florida law, a PPEC is described as a ''non-residential health care service prescribed by a physician for children who are medically and/or technologically dependent.''

PPECs represent an effort to reduce the isolation of homebound, medically dependent children and provide an opportunity for parents to continue participation in the workforce. Tampa's PPEC has a capacity to serve 24 children and provides services 12 hours a day, 5 days a week. PPECs are also being developed in other areas within the state. In addition to eligibility for state funds made possible by the new law, some private insurers are providing payment outside of the insured's benefit package to cover costs of care in the PPEC as an alternative to institutional care.

Expanding the availability of foster homes, group homes and medical day care for technology-dependent children is often dependent on whether a state has a licensure category for such facilities, has standards to assure quality and has health and safety regulations which address the unique needs of this population.

PHYSICIANS

The lack of physicians willing or capable of providing care in the community was consistently identified by parents and professionals as a barrier to home and community-based care for technology-dependent children. Two factors create this situation. First, there are many rural areas without an available physician. Secondly, where physicians are available in the community, few are comfortable with assuming responsibility for the comprehensive care of technology-dependent children.

Physicians may be available to children and families living in a metropolitan area or near a tertiary care hospital. However, many families have been unable to obtain physician services in their communities. This often reflects an unwillingness by physicians to provide care for a technology-dependent child because of medical/legal concerns; the unavailability of the education necessary to provide the specialized care; or an unwillingness to obtain the necessary education. As a result, technology-dependent children may be discharged from acute care hospitals to home without appropriate physician support or with inadequate routine and emergency care; or they may remain in the hospital ensuring access to physician support.

Tertiary and secondary care centers in some states are extending services to rural areas to assure patient access to physician services. In Iowa, for example, the University of Iowa Hospitals and Clinics has established 13 Regional Child Health Specialty Centers in the state. Location of these Centers throughout the state ensures that most families have access to a Center within a one-hour commute from their home. The University also serves the state with Mobile Child Health Specialty Clinics. In 1986-87, clinics were held in 26 cities. The clinics provided pediatric services and services to children with special health care needs. St. Luke's, a secondary hospital in Cedar Rapids, Iowa also provides outreach to rural areas with physician coverage and mobile health clinics. However, this approach to delivery of physician services in rural areas does not necessarily assure availability of physicians appropriately prepared to care for technology-dependent children.

Physicians cluster around major metropolitan areas and most specialists, whose primary or secondary professional activity is direct patient care, serve patients in hospital environments. The American Academy of Pediatrics (AAP), reporting 1985 membership at 35,616 pediatricians nationwide, found that less than 5 percent of their total number practice in nonmetropolitan counties with populations of less than 50,000. Furthermore, where a pediatrician or other physician may be available in a community, no incentives exist for that physician to invest the time to expand his skills to care for what may be a single and unique technology-dependent child for that community. Concerns relative to medical liability, lack of appropriate training and lack of acceptance and/or understanding of the concept of home care for these children all serve as disincentives for physicians to assume responsibility for care of medically complex, technology-dependent children in the community.

NURSING SERVICES

There is a shortage of registered nurses in the United States. This shortage is expected to worsen as enrollment in nursing education programs continues to decline. The number of nurses delivering direct patient care also continues to decline as many nurses seek alternate career opportunities including administration, education and research.

A technology-dependent infant or child in an acute care hospital is most likely to be located in a neonatal or pediatric intensive care unit where nursing care is provided by a registered nurse, pediatric nurse practitioner, or pediatric intensive care units where nursing care is provided by a registered nurse, pediatric nurse practitioner, or pediatric clinical nurse specialist. When that child is discharged home, the child's care is generally supported with nursing services ranging from 8 to 24 hours per day. This care is often provided by a community home care nurse with no special skills in the care of technology-dependent children. Transfer to home for some children may be delayed or prohibited because appropriate nursing services are unavailable in the community.

In most communities nursing services are provided by home health agencies, public health nurses or visiting nurse associations. The mission of these home care providers has traditionally been the provision of intermittent, short-term services to the geriatric population. As technology-dependent children move from acute care hospitals into the community, providers must expand their existing service agenda and adjust staffing patterns to meet the on-going, long-term service needs of this medically complex pediatric population. Families of technology-dependent children are compelled to locate and utilize the services of registered nurses to help support them in the care of their child at home. Many of these nurses have no experience in the care of technology-dependent children. Many parents report that they must often provide education for these personnel in the care of their child and in the use of specific life-support equipment.

The high cost of professional nursing services is also a factor to be considered in the provision of care at home for technology-dependent children. Nursing care is usually the most costly component of home care, ranging from $10 to $40 an hour. Cost savings to third-party payers have become an important factor in their willingness to finance intensive home care. Cost savings realized in home care programs relate to how much skilled care family caregivers provide. If all skilled care in the home were provided by registered nurses, for example, the yearly Medicaid payments for a family receiving 24 hours of nursing care a day would range from $112,000 to $245,000. However, if a family caregiver provides 12 hours of care a day, these costs could be reduced by half that amount.

While third-party payment for services in the home is usually associated with the licensing of the caregiver, parents, relatives and friends are routinely trained to perform such skilled tasks as suctioning, tracheostomy care, physical therapy, cardio-pulmonary resusitation and use and maintenance of equipment. Testimony before the Task Force has overwhelmingly supported the use of non-licensed professionals and non-professional personnel, trained for the care of a specific child, to provide services in the home. Non-licensed professionals and non-professional personnel in addition to family members, can safely provide specialized care under the auspices of an individualized care plan. Shifting most or all of the hands-on care to trained non-licensed professionals and non-professionals serves to direct the focus of the registered nurse to the development and supervision of nursing care plans and quality assurance. This shift should also result in more effective utilization of funding resources.

The barrier to home care created by the shotage of registered nurses has greater implications in rural areas where few home care providers exist. Programs designed to assure access to needed services for technology-dependent children and families in these areas are critical to avoid unnecessary hospitalization. A model program in the State of Florida — Rural Efforts to Assist Children at Home (REACH) — designed to assure access to appropriate care for chronically ill children within a 16 county area has been successful in avoiding unnecessary emergency room visits, clinic visits and hospital admission. REACH's program design focused on finding nurses indigenous to the rural community to be served and educating them to recognize and manage the problems of chronically ill children and their families. It emphasized integrating these nurses into the health care team at the tertiary care center to facilitate communication with the family and local health providers. It empowered nurses to act as consultants and liaisons with tertiary care professionals in addition to helping families understand and provide interventions necessary to manage their child's chronic health problem.

REACH presents a prototype for coordinated, community-based, family-centered case management in a rural area. It has been incorporated into Florida's statewide Children's Medical Services system and is being adapted to serve the state's frail elderly.

RECOMMENDATIONS

A full continuum of alternate care settings should be available to technology-dependent children. Care should be provided in the most appropriate, least restrictive, most supportive and nurturing environment.

The continuum of alternatives should allow ease of movement between care settings with the changing needs of the child and family. Whenever possible, this should be accomplished through utilization and development of existing systems.

- o **Congress should provide demonstration and grant funds to states through Title V, Maternal and Child Health authority, to identify available resources, to identify additional resources needed and to develop a strategy for meeting the needs of technology-dependent children. Demonstrations should focus on development of resource capability from existing systems.**

- o **Congress should promote the development of regionalized systems for coordinating/providing care.**

- o **Congress should promote the development of transitional units in hospitals, rehabilitation facilities, children's hospitals, and other appropriate facilities.**

- o **Congress should provide funding to expand foster care and specialized adoption programs and to recruit and train these families to provide care for technology-dependent children.**

- o **Congress should promote the development of non-institutional, home-like living environments such as groups homes for technology-dependent children.**

- o **Congress should promote the development and funding of specialized medical day care facilities such as the ''Prescribed Pediatric Extended Care'' facility.**

- **Congress should promote the development and funding of specialized medical day care facilities such as the ''Prescribed Pediatric Extended Care'' facility.**

- **The American Board of Pediatrics and other appropriate certifying boards should set standards for medical school curricula and post-graduate training programs for pediatricians, family practitioners and other relevant specialists in the care of technology-dependent children.**

- **Public and private funding should support continuing medical education (CME) for physicians in the care of technology-dependent children and their families.**

- **Congress should require tertiary and secondary hospitals receiving federal funds to develop rural outreach programs for technology-dependent children.**

- **Professional organizations such as the American Academy of Pediatrics should investigate and document the phenomenon of physicians not providing care to technology-dependent children because of medical/legal concerns. If appropriate, these organizations should pursue legislative relief to assure access to care for this category of children.**

The Task Force supports the delivery of care to technology-dependent children by non-licensed professionals and non-professional personnel appropriately trained in the care of a specific child. Care should be provided according to an individualized care plan. Nursing care plans should be prepared and supervised by registered nurses.

- **Congress should encourage states to use existing authority within Title XIX (Medicaid) to provide reimbursement for qualified, trained nonlicensed professional and non-professional caregivers who provide care under an individual care plan.**

- **Congress should provide funding through Title V, Maternal and Child Health, to develop standards, guidelines and training programs for certifying non-licensed professional and non-professional caregivers in the care of technology-dependent children at home.**

- **State nursing boards should be encouraged to develop service models which promote expanded roles for direct care providers other than registered nurses.**

- **Congress should provide funding through the Bureau of Maternal and Child Health for demonstration programs and/or grants to develop resources for the care of technology-dependent children in rural communities.**

CHAPTER VI

STANDARDS AND QUALITY ASSURANCE

INTRODUCTION

The feasibility of providing sophisticated medical technology outside of the acute care institution has been demonstrated case-by-case as innovative physicians and institutions seek to return the technology-dependent child to the care of its family. Parents and other non-professional caregivers are providing services once thought to be the exclusive responsibility of professional health care providers. Home care options and protocols have been developed for specific children in specific communities. Nevertheless, the Task Force has heard repeatedly of variable quality and hazards in hospital discharge programs as well as home care programs for technology-dependent children. Services and quality vary tremendously from state-to-state and often within a state.

The term ''standards'' is defined as those criteria that must be met either qualitatively or quantitatively prior to being judged in compliance with the Task Force's definition of appropriate care. These standards may relate to policy, personnel, job performance, program and process.

This chapter notes the barriers to uniform and acceptable quality home care for technology-dependent children and provides recommendations for developing and auditing standards for care of technology-dependent children.

BARRIERS

- Lack of nationally recognized and implemented minimal safety and performance standards for care at home or alternative environments for technology-dependent children.
- Lack of accountability for quality of care provided in the home or alternative environment for technology-dependent children.
- Lack of nationally recognized and implemented minimal safety and performance standards for equipment used in the home or alternative environment for technology-dependent children.

DISCUSSION

CARE AT HOME

In order to provide a uniformly safe and appropriate level of care for technology-dependent children, nationally recognized standards for both a process of care and for the practice of individuals involved in that process need to be developed, implemented, and audited for compliance and effectiveness. Currently, standards are either not available or are not widely recognized.

Standards which address quality of care must recognition the significance of the hospital community in accepting responsibility for discharge of the child to a home or home-like environment as the key institution in effecting a safe transition to home as well as being the guarantor that the child's care is transferred to a ''system'' capable of meeting the prescribed level of care and support.

Standards must recognition that it is the responsibility of society, acting through the medical community, to provide an environment that will support and protect the child from those phenomena that will adversely affect organ, system and child and family growth and development.

Standards should encourage the use of humane,comprehensive medical and developmental care in the home or least restrictive, home-like setting.

The role of the family and support of the family unit should be recognized in the development of standards of care. Encouraging family participation in discharge planning and the development of an individualized care plan; fostering family autonomy; and encouraging the goal of developing an integrated family with a strong parental sense of responsibility for and skill in the care of their child must be supported by standards written for the care of technology-dependent children.

Standards should address eligibility for care at home or alternative community settings. Eligibility may be functionally defined and should consider:

- The feasibility of providing, in the home, the level of support and intervention the child requires.
- The technology-dependent child's stability as defined by the ability of caregivers to provide the level of care expected for the child's disease process and its anticipated evolution.
- The parents' understanding of the child's prognosis.
- The involvement of the family unit as an indication of their willingness and capability for meeting the special needs of their child.

Standards should address the hospital discharge process. Hospital-based discharge programs should have written procedures and policies for discharge of technology-dependent children to their home or home-like community alternatives. The procedures and policies should provide for the development of an individualized discharge plan that addresses:

- Funding;
- Determination and acquisition of appropriate equipment and supplies;
- Designation of licensed professional and nonlicensed trained personnel for provision of care at home;
- Home-based rehabilitative, developmental, and educational programs;

- o Initial and on-going education programs for family members which focus on aspects of care appropriate to their defined responsibilities. This includes both knowledge-based and skill-based education modules and appropriate assessment tools;

- o Home environment safety;

- o Emergency services;

- o Transportation; and

- o Medical, developmental, and educational follow-up.

Hospital-based discharge procedures and policies should ensure documentation of all aspects of the discharge plan. Information and choices regarding each aspect should be available to the discharge planners and the family.

The discharge team should be interdisciplinary, include at least a physician, registered nurse and social worker and have one designated individual to provide overall coordination and ensure completion of the discharge program. The team may also include qualified developmental, rehabilitation, and respiratory therapy professionals, as well as others as needed. Parental, and where appropriate, patient participation in the interdisciplinary discharge process should also be assured through process standards.

Standards for home care management should address medical management, technologic equipment, professional and para-professional services, rehabilitative services, educational programs, ongoing family education, environmental support, emergency services, transportation for the child, and medical follow-up.

Standards for home care management should include a requirement for the development of an individualized care plan (ICP) ready for implementation for each child prior to discharge. The ICP should address each child's medical, rehabilitative, educational, developmental and social condition. It should include:

- o Child and family identifying information;

- o Summary of the child and family's current condition;

- o Assessment of the child and families needs,

- o Short and long-term goals to meet assessed needs;

- o Identification of services to meet the goals;

- o A plan for coordination of program components, such as education and health; AND

- o A statement of methodology to monitor progress of the ICP.

The ICP should be reviewed at least annually and when otherwise indicated by major change in the child's physical, developmental, emotional, or social status. Reviewers must include, but are not limited to the parents or designated caregiver, the physician, case manager and the third party payer representative.

Standards for home care management should identify an interdisciplinary home care team. At a minimum, this team should include a parent or alternate caregiver, physician and case manager. This team is responsible for defining short and long-term goals for the child and family which are reviewed, explained, and adjusted for compatibility with the family's perceived needs and goals.

ACCOUNTABILITY FOR QUALITY OF CARE

Information received by the Task Force leads us to conclude that the lack of standards for the care of technology-dependent children may result in the provision of unacceptable or substandard care. As a result, children are exposed to morbidity and death while third party payers continue to fund substandard interventions. A lack of accountability for quality of care produces abuse, morbidity and mortality, and unnecessary depletion of financial resources.

We believe that quality assurance mechanisms should be an integral part of both institutional and community-based programs and should be defined for all essential services and caregivers, both professional and non-professional. Professionals should be certified by appropriate state, local or institutional certifying bodies as qualified to meet their assigned responsibilities in the care of technology-dependent children. Standards of care for technology-dependent children must also address a process for certifying or otherwise affirming that nonlicensed professionals or non-professional caregivers receive education/training appropriate to their responsibilities.

Third-party payers also have responsibility to assure that services for which they provide reimbursement meet quality standards. Reimbursement should be available only for services provided by properly certified individuals or organizations. The Task Force would also encourage third party payers to maintain data bases to ensure that billings for services are within established norms for these services.

Standards should exist for third-party payers which will ensure counseling of families on options and alternatives that would provide services while protecting them from depletion of financial reserves.

EQUIPMENT STANDARDS

Western society has relied upon national and international standards for design specifications, quality of performance and durability for a wide variety of products designed for use in the hospital. No such standards exist for equipment or equipment maintenance schedules provided for use in the home or non-hospital alternatives to home.

The unique and changing physiologic needs of technology-dependent children require certain types of medical equipment. These devices should perform their intended task with minimal risk of either failure or harm to the patient. They should be sturdy, reliable, easy to maintain and portable.

Testimony before the Task Force identified incidence of medical device failure in the home with the threat of injury or death to the child. This experience has been shared by most physicians actively involved in the use of equipment for life support in the home or home-like environment.

At present, probably due to low market volume, equipment designers and manufacturers have been reluctant to devote sufficient research and development effort to the special requirements of technology-dependent children. As a result, equipment designed for adult use is adapted to the needs of small infants and children. Available equipment often lacks desirable and even necessary versatility and safety features.

Medical devices are regulated by the Food and Drug Administration (FDA), under authority of the 1976 Medical Device Amendments to the Food, Drug, and Cosmetic Act. Within FDA, the Center for Devices and Radiological Health is charged with consumer protection related to hazardous or ineffective devices. However, guidelines or regulations for communicating design aberrations or malfunction of equipment used in the home are not readily available to professionals or consumers.

The Task Force believes that a federal oversight agency should promote and facilitate the development of voluntary standards through private organizations such as the American Society for Testing and Materials, Joint Council on the Accreditation of Healthcare Organizations (JCAHO), National Association for Medical Equipment Suppliers (NAMES), American Association for Respiratory Care, American National Standards Institute, Association for the Advancement of Medical Instrumentation, Compressed Cas Association, International Standards Organization and the International Electrical-Technical Commission. Durable medical equipment (DME) professional organizations should be encouraged to develop and adopt standards which address their full spectrum of provider involvement and responsibility in the provision and maintenance of durable medical equipment, including routine maintenance. A lead agency within the federal government should be designate to monitor and evaluate equipment and device safety and reliability and ensure a mechanism for communication between equipment and device manufacturers and consumers.

RECOMMENDATIONS

o **National standards should be developed and implemented for the hospital discharge and home care of technology-dependent children. These standards should be developed through the aegis of the Bureau of Maternal and Child Health and Resources Development (MCH) of the Department of Health and Human Services and should involve the direct participation of health care providers and consumers.**

o **The Health Care Financing Administration and designated State agencies should develop a mechanism of quality assurance in the provision of appropriate care to technology-dependent children beginning with discharge from the hospital and continuing at home or in a home-like environment.**

o **Congress should provide funding through the Bureau of maternal and Child Health to facilitate the development of quality assurance standards relevant to the provision of appropriate care for technology-dependent children being discharged from the hospital or living in a home or home-like environment.**

- Congress should require all State Medicaid programs to ensure that all health care providers delivering services to technology-dependent children have quality assurance programs appropriate to their service role.

- Congress should provide funding for a work group representing private organizations, providers and consumers to develop voluntary consensus pediatric standards for minimal safety and performance of equipment used in the home or home-like environment. The Food and Drug Administration should function as the federal oversight agency responsible for facilitating this process.

- Congress should require the Food and Drug Administration to develop national regulations to ensure rapid and ongoing communication between manufacturers of equipment and consumers regarding equipment hazards and other product safety information.

- State agencies and private organizations should be encouraged to implement standards and mechanisms to ensure the safety of equipment and adequacy of maintenances schedules.

- States should be required to maintain a registry of Medicare/Medicaid certified DME suppliers who provide services to TDC. This list should be available to the public and address the level of service competence that each DME equipment company is qualified to deliver as set forth by a voluntary program which would be available to all DME companies through NAMES. Level of competency should be categorized by service capabilities and available equipment.

- States should require certification of DME providers for participation in home-care programs for technology-dependent children. Certification should occur through a certifying body such as NAMES, JCAHO. The certification process should include a rating system to rate the level of competency in each type of available service. It should also require in-service training programs for varying levels of personnel involved with the delivery of services and for in-home supervision of equipment used by technology-dependent children.

- Third-party payment should be withheld for services or delivery systems that do not meet jointly established (third-party payer and provider) guidelines for the provision and maintenance of durable medical equipment.

CHAPTER VII

CASE MANAGEMENT

INTRODUCTION

The single most important aspect of appropriate care is case management. Deliberations by the Task Force continually returned to the necessity for a family-centered, community-based coordinating process if appropriate care is to be assured for technology-dependent children. The following were identified as major barriers to access to high quality, comprehensive medical, social, educational and related services.

BARRIERS

- Lack of an organized system to assure coordination and monitoring of all needed services and funding sources, communication among providers, continuity of care and management of multiple funding sources.

- Lack of focus on the needs of families.

- Inadequate or inappropriate discharge planning and follow-up.

- Lack of coordination and communication between state agencies, schools, medical and other related service providers in the private and public sectors.

- Lack of flexibility in interpretation of eligibility for benefits by insurers, Medicaid, Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) and health maintenance organizations (HMOs).

DISCUSSION

The increasing number of children with complex medical and technological needs has posed a tremendous challenge to existing service and financing programs. Programs are developing or expanding incrementally as policymakers respond to the demand for services for these children. These programs are experiencing difficulty in keeping pace with both rapidly advancing medical technology and enhanced skills of providers responsible for the increasing survival and continuing care of these children. The resulting patchwork of programs has intensified the complexity of the service delivery system. Parents with technology-dependent children are faced with the tasks of identifying available programs and resources in their area; and successfully navigating the maze of programs in order to assemble a complex package of services for their child. Some parents are successful in this process. Many others are frustrated by their inability to identify appropriate services, overcome bureaucratic roadblocks in obtaining identified services and resources, and/or managing a multiplicity of providers, services and third-party payers.

Public testimony and documents received by the Task Force were unanimous in emphasizing the lack of a family-centered coordinating process as a significant barrier to appropriate care not only for technology-dependent children but for most chronically ill children. The need for such a process received national attention in 1982 with the Surgeon General's Conference on ''Children with Handicaps and their Families.'' A recent study by the Office of Technology Assessment on technology-dependent children determined that ''coordination and oversight of the package of services provided to an individual is a vital service'' and can ''sometimes minimize the costs of care for children already being cared for at home.''

This coordinating function, commonly referred to as ''case management,'' is a fairly recent concept in the provision of health care and related services. In spite of the national attention it has received, there is no single widely accepted definition.

Definitions vary within case management systems. A system's focus may be cost-containment, benefits expansion or coordination, family support, advocacy and/or monitoring of services. At present, case management systems are closely focused on cost-containment through substitution of less costly medical services. Whatever the impetus for current programs, case management systems are being developed and implemented for targeted groups in many areas across the country.

The development of case management systems emphasizing family-centered, coordinated, community-based care has been fostered by the Bureau of Maternal and Child Health and Resources (MCH), Department of Health and Human Services. MCH has been instrumental in the development of comprehensive, coordinated systems for case management for technology-dependent children. In 1983, three projects under Special Projects of Regional and National Significance (SPRANS) were sponsored in Maryland, Louisiana and Illinois. The goals of these projects were to develop and implement regionalized systems of comprehensive, coordinated home care for ventilator-assisted children, to assure access to appropriate care for these children and to reduce costs.

Third-party payers are also recognizing the need to provide alternatives to existing benefits packages. In order to provide cost-effective alternatives to hospital care for certain specific chronic conditions, many insurers are now offering a ''case management'' service (i.e., benefits management) directed toward high cost hospitalized beneficiaries in an effort to provide coverage of more appropriate, less costly services. Using ''exceptions'' to standard benefits, these insurers fund home or community-based care for a medically stable patient instead of more costly in-hospital care. Currently, less than 20 percent of private insurers have incorporated this service into their overall benefit plans.

In addition, many states have developed case management systems targeted to populations with high-cost health care to more effectively manage resources while continuing to assure access to high quality care. Several recently enacted amendments to the Social Security Act have provided impetus to this process.

- Under the Home and Community-based Waiver program authorized by Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (OBRA) (P.L. 97-35), state waiver programs may include a case management service. States have the latitude to define case management according to their own interpretations.

- The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)(P.L. 99-272), Section 9508, provides states the option of providing case management to recipients of Title XIX (Medicaid) without the need for a waiver. Case management is defined as ''services which will assist individuals eligible under Title XIX in gaining access to needed medical, social, educational and other services.

  The intent of Congress in passing this legislation was that states not use case management ''solely to reduce costs,'' but that the system be responsible for ''locating, coordinating and monitoring'' services for targeted groups.

- Funding was also made available to states under Section 9441 of the Omnibus Reconciliation Act of 1986 (ORA)(P.L. 99-509) amending the Title V Maternal and Child Health (MCH) Services Block Grant to ''promote the development of community-based services networks and case management for children with special health care needs.'' This legislation defines case management as: ''services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children and their families.''

- And, finally, the Education of the Handicapped Act Amendments of 1986, P.L. 99-457 does not define ''case management,'' but assumes the participation of a case manager in the multidiciplinary planning for ''family-centered, coordinated, community-based'' integrated health and education services.

The Task Force emphasizes the importance of a comprehensive, family-centered, community-based system to coordinate care and service delivery for technology-dependent children. An effective coordinating system, available to all technology-dependent children and their families, is critical to overcome barriers to appropriate care and services. Such a system should enhance the quality of care and provision of services.

Although cost-savings may be realized through the effective and efficient organization and utilization of resources, decisions to develop such systems across the nation should not be motivated only by the potential for cost-savings. Of equal importance is the potential for ''cost-avoidance'' through reducing potentially avoidable reinstitutionalization, and assuring that the client receives necessary services without inappropriately utilizing costly resources.

This ''cost-avoidance'' can be realized through a case management system that is goal-oriented, has a process of needs assessment and organizes, coordinates and monitors service delivery based on measurable objectives. This system selects services to meet the needs of the child and family. This alone can serve to reduce misutilization of resources as families are often required to use specified services to ensure eligibility for other needed services. Case management is a dynamic process, with the child and family at it's center, moving along a continuum of assessment → goal setting → delivery of services → evaluation → reassessment.

To ensure a common interpretation of effective case management in this Report's recommendations, case management is defined as:

- A goal-oriented process which promotes the effective and efficient organization and utilization of medical, social, educational and other resources to achieve or maintain the maximum potential of the child in the most appropriate, least restrictive environment.
- A process of service coordination that is community-based and family-centered, and identifies a single individual (case-manager) for each technology-dependent child and family.
- Providing active advocacy on behalf of the child and promoting active communication among providers, payers, the child and family.
- An interdisciplinary planning process that includes the family and local care providers.
- A process which ensures the development of an individualized care plan that is goal-directed, based on a comprehensive assessment, contains measurable objectives and is reviewed regularly and on an ''as needed'' basis.
- A process which identifies gaps or deficiencies in the array of community services and assists with resource development.
- A process which includes quality care assurances and appropriate monitoring and evaluation mechanisms.

The Task Force believes it is inappropriate to set specific descriptions for the role of case manager, specific educational/professional background requirements or agency affiliations. Case managers may change depending on location and condition of the child and the needs of the child and family. The degree of hands-on involvement by the case manager should be based on the families need for their service. Ideally, a case management system should:

- Assist the family, to the extent feasible, to assume responsibility for components of their child's care. The case management system should assure the availability of assistance for the family when needed.
- Have current information on availability of funding from all sources.
- Participate in the development of a discharge plan and transfer/follow-up to the next appropriate level-of-care.
- Participate in and assure the development of an individualized care plan.
- Coordinate community-based medical, psychological, social and educational service delivery in accordance with the plan of treatment.

- Monitor and evaluate all phases of the individualized care plan, including performance of the case manager.
- Provide or arrange care-giver training.
- Be a prudent purchaser of multiple services and devices.
- Assure continuity of care.

Further underscoring the need for an effective case management system is the fact that services for children are traditionally dispersed among various state agencies which often have overlapping and contradictory mandates and responsibilities. This organizational structure results in programs serving children without coordination and may seriously hamper access to appropriate coordinated care for technology-dependent children. Testimony before this Task Force indicated that this lack of coordination among agencies is a major barrier to appropriate coordinated care. Agencies will often deny services based upon their determination that responsibility for services is located in another organization. It was further presented in testimony that interpretation of agency policies is often inconsistent within a state, resulting in differing availability of services within states. This testimony is supported by recent studies which revealed that gaps, inconsistencies and inequities do exist in service delivery systems.

The Task Force strongly emphasizes the importance of promoting coordination among programs and agencies involved in delivery of and payment for services to a technology-dependent child. A multidisciplinary, interagency approach to the development of a service plan specific to each child and family is essential to the well-being and successful integration of a technology-dependent child into the community. This concept is supported by 1986 Amendments to the Education of the Handicapped Act, Public Law (P.L.) 99-457, which seeks to promote the development of a continuum of services that will assure ''universal access to comprehensive services for all handicapped children.'' Such models also exist through regional or state programs or centers for the developmentally disabled such as those operated in many states by Federally supported University Affiliated Programs.

RECOMMENDATIONS

The Task Force strongly recommends the development and implementation of a comprehensive, community-based, family-centered case management system for technology-dependent children in each state. We support the intent of Congress (Report 95-315) implicit in the passage of the Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) to assure ''universal access to comprehensive services for all handicapped children.''

The Task Force further recommends that Congress move one step further to require that states develop and implement a program of comprehensive, community-based, family-centered case management to meet the special health, developmental and educational needs of technology-dependent children.

o Children identified as technology-dependent and their families should be categorically eligible for the case management service.

o Where feasible, states should be encouraged to provide this case management service through a private or public agency having no financial interest (either as a provider or payer) in the coordinated services.

o The programmatic responsibility for organizing and monitoring the system of case management should be assigned to the states' Title V Maternal and Child Health agencies for children with special health care needs.

o Congress should require the Bureau of Maternal and Child Health to provide policy and program development, coordination and oversight of this process at the Federal level.

o Congress should provide special funding through Title V, for the Children With Special Health Needs program in each state in order to identify and certify regional, comprehensive, coordinated systems for the delivery of care; to be the Agency serving as the single point of access to the certified service delivery network; and to include within the system a plan to promote collaboration among appropriate providers of services (medical, education, social services, etc.) and public and private funding agencies.

o Congress should require state Medicaid agencies to contract with the Crippled Children's Service (CCS) to provide this coordinating service for technology-dependent children covered by Medicaid.

o Congress should require state and local agencies that receive Federal funds for children's services to cooperate with the implementation of an eligible child's individualized care plan.

o Congress should encourage states to identify resources for technology-dependent children and ensure that various agencies within the state are coordinating both their responsibilities and resources in the best interest of the child.

CHAPTER VIII

DEVELOPMENTAL/EDUCATIONAL SERVICES

INTRODUCTION

The Task Force identified developmental and educational services as essential elements in the provision of appropriate care for technology-dependent children. They determined that the goals of developmental services should be to:

- Foster the maximum social and educational development of technology-dependent children, and
- "Mainstream" them into community schools where possible.

Public schools are the dominant system providing education and related services to technology-dependent children. However, from system-to-system and state-to-state, there are many differences in the organization of services, procedures for identifying students, cooperation with other agencies and relationship with families. This chapter reviews a variety of issues pertaining to the delivery of developmental/educational services to technology-dependent children.

BARRIERS

The Task Force found that the provision of appropriate developmental/educational services were restricted by:

- Lack of attention to developmental needs during acute care hospitalization.
- Attitudes of professional staff who are medically competent but lack knowledge of developmental needs.
- Reluctance of school systems to admit technology-dependent children
- Poor coordination of health-related services in schools.
- Lack of federal/state guidelines on where the responsibility lies in the provision of and payment for services to a technology-dependent child in school.

DISCUSSION

The long-term developmental and educational benefits of providing early intervention for handicapped infants and children are well known from published findings of basic research. Studies of the effectiveness of preschool education for the handicapped have demonstrated the educational and economic benefits of programs for handicapped children.

Prior to the passage of The Education for All Handicapped Children Act (P.L. 94-142) in 1975 requiring free, appropriate educational services in the least restrictive environment for children 3 to 21, many children with chronic illnesses and handicapping conditions were excluded from public school or provided inappropriate and incomplete educational services. Since 1976, public schools have attempted to provide as much education and related services in regular schools as possible for these children. Enactment of the Amendments to the Education for All Handicapped Children Act (P.L. 99-457) in 1986 expanded this legislation to include children from birth to age 3.

In recent years, the small number of technology-dependent children have presented yet another special challenge to the educational system. Because the number of these children is relatively small, school policies are often developed individually, to meet the needs of a specific child.

The Federal mandate of P.L. 94-142, combined with professional concerns for normalization of treatment and educational experiences, has resulted in heightened concern about the appropriate way and place to provide educational opportunities for technology-dependent children. The successful placement of and programming for a technology-dependent child are dependent on the coordination and cooperation of the three service delivery components of the school system, the family and health professions.

Currently, technology-dependent children are often inappropriately placed in special education classes or not admitted to their community school. This occurs because of unresolved conflict regarding:

- the appropriateness of teachers providing health care services;

- the responsibility for payment for in-school nursing attendants, and

- the unwillingness of school administrators and/or teachers to assume responsibility for care needed

Issues regarding the definition of and extent to which schools are responsible for providing health related services are still matters for debate. Much of the debate has centered on the requirement under P.L. 94-142 that places responsibility for provision of ''related services'' on the educational system. ''Related services'' are those services that must be provided to minimize the adverse effect of the health condition on the child's participation in school. While nursing services are a subset of the many ''related services'' guaranteed to children in need of special education under P.L. 94-142, whether services such as catheterization, tracheostomy care and suctioning are implied in this language has been interpreted differently school district by school district. However, there is a growing body of case law supporting the provision of such services by the school systems.

Throughout the United states there is great variability in the way the states and the local school systems have organized educational and related services. A 1985 survey of state education and health departments indicates that:

- o Few states, 12 percent, have guidelines for selected nursing procedures in school such as catheterization, seizure management and respiratory care.

- o 14 percent are developing in-school nursing guidelines.

- o 26 percent have guidelines for administering medication.

- o 26 percent had no guidelines.

Some school administrators, teachers and school nurses are reluctant to assume responsibility and provide health related services for children with complex medical needs. Many feel that delivery of health care services by educators is inappropriate. Still others are concerned with the safety of technology-dependent children being served in public schools and possible liability issues. Questions regarding identification, training and supervision of providers of health care services in the school setting remain unresolved. Further complicating these issues is disagreement on what agency is responsible for reimbursement of health care services provided in the school. The scope of the school systems responsibility to provide and assume financial responsibility for health care services has not been clearly articulated. On the other hand, Medicaid, as payer of last resort, may deny payment for a health care service provided at school on the grounds that it is within the schools systems responsibility.

Although P.L. 94-142 and P.L. 99-457 require an individualized education in the least restrictive setting, current practice ranges from excellent programs in regular public schools to the purchase of services from private providers in highly segregated settings. Several factors have influenced how services to technology-dependent children are provided through the public school system. Perhaps the most fundamental of these has been the growing recognition of the importance of family participation in the educational process. Parent/professional relationships have often been adversarial with parents either completely excluded or given a minor role in the intervention process.

While professional training and administrative policies often work against a real parent/professional partnership, the necessity of parental involvement in the planning, implementation and evaluation of services for their child is increasingly being viewed as critical. This is supported by P.L. 94-142 and P.L. 99-457 which define roles for the family. As the concept of family-centered, coordinated community-based care continues to grow, professionals and families need to work cooperatively in defining their roles as providers of services to technology-dependent children.

Also effecting how services are provided through the public school system is the development of education strategies specific to students who are technology-dependent. There is a movement away from a rigid curricular approach to a more flexible process that emphasizes individualized programming based on assessment of the needs of the child and family. The Task Force believes that developmental/educational services are an appropriate component of the individualized care plan. Cooperation between the school system, parents and community health care providers is critical in developing that plan.

The Task Force concludes that access to developmental and developmental/educational services for technology-dependent children should be ''setting independent.'' That is, appropriate services should be provided in whatever setting the child is at any given time. The developmental/educational needs of infants and children in acute care facilities are often overlooked by professional staff who focus on the child's medical problems. Attention should be given to assuring access to appropriate services in acute care hospitals as soon as the child's condition permits. Furthermore, technology-dependent children should have access to home programs regardless of the anticipated time out of school.

Currently, little incentive exists for school personnel and health care providers in the community to collaborate on the development of an individualized care plan for a technology-dependent child. To assure the success of the child's functioning in the school, teachers and other early childhood professionals need to maintain close, ongoing communication with medical and other health care providers about the child's health status. One step in developing a forum for this cooperation is provided in P.L. 99-457 which requires the development of an interagency Early Intervention Council in each state to ensure that states provide a comprehensive system of early intervention for handicapped infants.

The Council must include representatives of each public agency within the state which is or should be providing services to handicapped infants, as well as individuals concerned with the needs of these children. This latter group includes parents, private service providers, professionals and child advocates. A similar working group is being considered on a National level to include those Federal agencies concerned with the delivery of health and educational services to handicapped infants and toddlers.

RECOMMENDATIONS

The most important variable in assuring appropriate developmental/educational services to technology-dependent children relates to the degree to which professionals, their agencies and the families can form an effective programming partnership. The debate about the provision and payment for services to this population centers on the fact that no agency has been given a clear mandate to provide these services.

o **Congress should require, through the Department of Education, Office of Special Education and other Federal agencies collaborating on implementation of P.L. 99-457, the establishment of a joint education/health work group for the purpose of developing a joint policy statement that:**

   1. **recognizes that technology-dependent children are entitled to and belong in public schools;**
   2. **identifies local or state-by-state reimbursement and service delivery barriers that need to be overcome to ensure that these children receive appropriate developmental/educational services independent of their ''care setting;''**
   3. **identifies agency responsibilities that will overcome these barriers, and**
   4. **assures continued collaboration and cooperation.**

- Congress should require penalties for noncompliance in the monitoring of states compliance with P.L. 94-142 and P.L. 99-457.

- Congress should encourage states to review existing school health procedures and develop guidelines that ensure care of technology-dependent children in schools.

- Congress should provide funding, through the Department of Education, Office of Special Education with assistance from Title V, Maternal and Child Health, to assist states in identifying and developing appropriate in-service training for all school personnel who interact with the technology-dependent child. Guidelines for school-based training should provide for training tailored to a specific teacher's needs concerning a specific child.

- Congress should clarify the coordination of benefits and financial relationships among Title V, Title XIX, the Education for all Handicapped Children, Head Start and other relevant programs for support of health care services to technology-dependent children.

CHAPTER IX

FAMILY SUPPORT

INTRODUCTION

Traditionally, health care professionals have managed American health care, making treatment decisions, providing care and regulating communication and information to patients and families. This control of the health care system failed to recognize the importance of the family unit in the successful outcome of health care services, especially for chronically ill and/or handicapped children. The system is changing as medical care and technology advance.

The concept of family-centered care has evolved with increased awareness of the psychological and social components of health. This, together with recognition that the family is the one constant in a milieu of changing health care providers, professionals and agencies, directs the system to support the role of families in the care of chronically ill children.

The Task Force defines ''family support'' as ''services, resources, information, training and emotional support that enables a family to assume responsibility and provide care for a technology-dependent child in addition to meeting goals and accomplishing tasks of family life.''

This chapter focuses on the barriers to family support and the scope of services necessary to support families in their caregiving role.

BARRIERS

Testimony before this Task Force identified the need for an accessible and responsive family support system. The following were identified as barriers to family support services:

- Lack of a consistent mechanism to support parents in decision-making with physicians and other health care professionals.

- Lack of a ''partnership'' between parents and professionals in planning of care for technology-dependent children.

- Lack of family support systems both in institutions and at home, including psychosocial counseling, support groups and networking for families.

- Lack of up-to-date, practical information on community services and sources of family support.

- Lack of family training programs for planning and providing appropriate care.

DISCUSSION

Few events can be so devastating for parents as the birth of a severely medically compromised infant or the onset of a life-threatening illness or catastrophic injury to their child. The survival of many of these children often presents complex issues and questions related to care and medical support. The process of decision-making on the appropriateness and humaneness of medical intervention is a subject of national debate. Traditional mechanisms for making such decisions have been informal and, in many circumstances, viewed as inadequate in addressing the medical issues and decisions in care. The Task Force believes that a mechanism to support parents and facilitate decision-making is a critical component of a family support system.

An important aspect of family support is an on-going exchange of information between parents and professionals focusing on the best interest of the child, and assuring the existence of informed consent. Parents consistently identified problems in their ability to obtain complete, pertient information about their child's diagnosis and predicted outcomes of treatment. Physicians frequently cited the difficulty in determining long-term patient outcomes, with long-term outcomes often not fully understood for at least five to eight years. Decisions are further complicated by individual judgements regarding treatment of severely compromised infants and children, by established practices and philosophies of acute care institutions and by rapid advancement in technology, changing treatment and survival of the most critically ill.

Within the past several years, ethics committees have been established within many institutions. In an effort to bring objectivity to decisions on care and advanced life support, such committees have the potential to function as a support system for the child, family, physician and hospital personnel. Currently, about 70 percent of all hospitals have ethics committees.

The Task Force believes that parents are entitled to receive all information regarding their child's diagnosis, treatment interventions and prognosis in understandable terms. We support the establishment of a collaborative process within medical institutions to facilitate parent/professional communication, decision-making and support.

A commitment to the development of mechanisms within the community to support and sustain the family unit is also necessary if parents are to care for their technology-dependent child at home. Crucial to this commitment are:

- Acceptance of the concept of family-centered, coordinated community-based care, by hospitals, physicians and community agencies;

- Development of a parent and professional partnership in planning and providing services for the technology-dependent child;

- Training and preparation of parents and other appropriate family members as caregivers; and

- Establishment of a comprehensive information network.

The success of family-centered, coordinated community-based care is largely dependent on the degree to which parents and professionals form a collaborative alliance to assess and meet the needs of technology-dependent children. This is often a new role for professionals and parents. Professionals have traditionally controlled the delivery of services with little or no input from the parents. In this environment, parents have often felt disenfranchised and incapable of influencing their child's care.

The level of parent participation often depends on the commitment of professionals to encourage and support parents in this role. Clearly, many professionals work effectively with parents on the care of an individual child. Some parents are influencing how, when and where services are provided. They are assuming responsibility for delivery of complex medical therapies, negotiating with financing agencies and contracting for service providers in the community. For other parents, relationships with professionals may be less than supportive, as these parents often lack the confidence to assume a prominent role and/or may be excluded from care decisions by professionals. This lack of parental involvement in the decision-making process may result in programs of care for the child that are unrealistic and unachievable.

Promoting parental involvement and facilitating parent/professional collaboration is an important component of family support. Various programs are addressing this issue. A project of the Federation for Children with Special Needs in Boston, Massachusetts, entitled Collaboration Among Parents and (Health) Professionals (CAPP) is developing training programs and workshops to prepare parents to assume an integral role in the health care of their children, and promote communication and collaboration among parents and health care providers. Goals of a similar program by The Association for the Care of Children's Health (ACCH) in Washington, D.C. include promotion of family-centered care of children with special health care needs and parent/professional collaboration.

Some of the resistance by professionals to include parents in the decision-making process may be a result of their lack of knowledge and experience in working within a collaborative process, and the non-reimbursed time that this requires in institutions that are increasingly concerned with funding issues. Still others may question the validity and objectivity of parents in meeting this responsibility. Professionals providing services in the home and community need specialized training to build skills in working collaboratively with families and other service providers in the development of individualized care plans for technology-dependent children.

Most pre-service and in-service training curricula do not provide sufficient education in these skills. Programs like the Chronic Illness Teaching Program (CITP) at Michigan State University are designed to bridge this gap through a primary care pediatric residency program. CITP focuses on the developmental and behavioral aspects of children with chronic illness and their families. Among other objectives, this program seeks to promote an understanding of the impact of chronic illness on the child, family, service providers and society, and an understanding of coordinating care with the family and other health, education and community professionals. An important component of this program is a three-year, in-depth experience for the pediatric resident with a chronically ill child and the family.

Reshaping of professional attitudes and acceptance of parental involvement is also occuring informally as successful partnerships emerge between parents and professionals in the care of a technology-dependent child. Conferences like the annual ACCH Parent Network Meeting provide a forum for parents and professionals to share information and feelings on issues related to children with disabilities.

Clearly, a parent/professional partnership in articulating the needs of the child and family is necessary to develop an effective program of care. Parents able to care for their technology-dependent child at home have strengths and weaknesses that effect their ability to provide that care. These strengths and weaknesses should be considered when developing an individualized care plan. To be efficient and cost-effective, a system that encourages home or community-based care for technology-dependent children must be flexible enough to build on a families strengths and provide support where necessary.

Witnesses before the Task Force also identified the need for a systematic approach to caregiver training. To ensure a safe transition of technology-dependent children from the hospital to home, parents and other caregivers must be able to capably deliver routine and emergency care. Currently, most training is fragmented, with each professional or hospital center determining training needs and how training is provided. Furthermore, after the initial training in use of sophisticated machines and observation skills, little opportunity is provided for parents to update their skills or knowledge base. And, in some cases, parents have received little or no preparation.

Widely accepted guidelines on initial and on-going training needs for parents and other non-licensed caregivers of technology-dependent children do not exist. Responsibility for certifying the caregivers skills and training vary from place to place. The development and use of organized teaching plans or checklists for specific conditions and care needs would standardize teaching needs and the level of learning required for caregivers. Effective training programs build parent competence, and confidence, in their ability to deliver safe, appropriate home care.

Another important component of an effective family support system is the availability of and access to psychosocial counseling and support groups. Stress can be a major problem for the families of technology-dependent children regardless of how well prepared they may be for assuming care at home. Families often characterize themselves as being socially isolated, powerless to control their lives and in a perpetual state of grieving. Withdrawal from normal social situations often occurs. Family and marital stress may result in a breakdown of the family unit.

Insufficient attention has been given to the effects of stress both on the family and on the physiological and psychological outcomes for the technology-dependent child. The role of social support as a defense against the effects of stress is, however, gaining attention. Supportive social networks have been linked to positive health related outcomes, better compliance with prescribed medical regimens, improved psychological outcomes in children with chronic illness, and positive parental interaction with their children. There is also evidence to suggest that the efficacy of medical, developmental and educational services provided to a technology-dependent child depends on the psychosocial support provided to the child and family.

The Task Force believes that assessment of the child and families psychosocial needs and services to meet those needs should be part of an individualized care plan. Access to formal services should include counseling, mental health assistance, specific therapy and respite care.

Equally important is the availability of and access to parent-to-parent support groups. Families of children with similar conditions and families who have adapted to care of a technology-dependent child at home can encourage, educate, share information and help to dispel feelings of isolation. Innovative programs such as the Family Friends Project sponsored by the Robert Wood Johnson Foundation offer a cooperative approach to support. This project is a system of tri-generational support in which senior citizens provide companionship to chronically ill children and their families. A community family support system should include capacity building of both those services reimbursed by third party payers and voluntary organizations.

The Task Force determined that parent networking is a necessary adjunct to the provision of appropriate care for technology-dependent children. Because the needs of technology-dependent children are sufficiently diverse and complex and the current system so fragmented, the provision of quality services requires communication, coordination and interaction among a broad range of organizations and agencies.

Networking serves several important purposes. First, access to resources and services is expanded through exchange of information. Second, it creates an awareness of needs and builds support for needed action. Third, it provides a forum for parent-to-parent support and parent/professional dialogue. And, fourth, it enhances families ability to manage their child's care at home.

Networking activities may also include sibling support programs, family resource libraries and sponsoring cooperative purchases of equipment and supplies. Assistance in developing community networks is provided through the National Center Network Project at Georgetown University. This project has developed a series of workbooks focusing on network development. It also provides training, technical assistance and resource materials for family-centered programs.

Parent-to-parent support groups are an important component of family support. Such groups have often been the origin of what have expanded into formal, institutionalized services. Support groups enable parents to compare experiences and become better consumers of health care options. Since parents have almost never previously known anyone with a child in a similar situation, there is no intuitive sense of how services should be arranged and delivered. Support groups can enable parents to discern common concerns and advocate strategies for change.

While in-person support groups can be viable in urban/suburban environments, the low incidence of this population may make this an unreasonable expectation in rural communities. For these rural areas, parents may need to affiliate with more generic support groups and/or develop a telephone relationship with parents in other parts of the region.

RECOMMENDATIONS

- Foundations should be encouraged to study: the efficacy of hospital ethics committees; inter-institutional reliability of ethics committees; the decision-making process of ethics committees as they relate to technology-dependent children; and parental access to and involvement in ethics committees.

- The American Board of Pediatrics should develop and require courses and practical experience in the special health and related needs of technology-dependent children. These programs should include the importance of developmental processes, psychosocial care and communication/collaboration skills.

- The National League of Nursing and the American Nurses Association should develop and require courses and practical experience in the special health and related needs of technology-dependent children. These programs should include the importance of developmental processes, psychosocial care and communication/collaboration skills.

- Professional organizations and home health agencies should be required to conduct in-service and continuing education courses that build skills in serving technology-dependent children and their families.

- State health departments should develop education modules related to the care of technology-dependent children that could be distributed to communities on an as needed basis.

- Guidelines that provide for systematic training and continuing education of parents and other non-professional caregivers should be developed by a consortium of professional groups and parents of technology-dependent children.

- Institutions caring for technology-dependent children should provide parents with procedures, policies and protocols related to home care.

- Third party payers should include in their benefits packages access to counseling and other mental health services for families of technology-dependent children as part of the overall individualized care plan for the child and family.

- Federal funds should be made available under the Title V, IX-15

- MCH should continue to fund projects and meetings to promote and expand collaboration and cooperation between public and private agencies, professionals and parents.

CHAPTER X

RESPITE CARE

INTRODUCTION

Reports to the Task Force from families of technology-dependent children and professionals emphasized the existence of family stresses and disruptive changes in the functioning of families of technology-dependent children.

The Task Force identified respite care as a critical element in the provision of appropriate home care for technology-dependent children. Respite care is defined by the Task Force as:

- A service for the family that provides an alternate to or substitute for family caregiving responsibilities of their technology-dependent child on a planned or unscheduled basis. It may take place in the home or other appropriate location. This service should be provided by individual(s) with qualifications appropriate to the provision of the child's care.

- A component in the continuum of appropriate care for the technology-dependent child and included in the individualized care plan.

BARRIERS

Barriers to the provision of respite care were identified as:

- Nonavailability of respite care services, both in-home and/or other locations.

- Lack of awareness of existing respite programs.

- Absence of funding for respite care services by third-party payers.

- Lack of a widely accepted definition of respite care.

DISCUSSION

Home care programs provide options for the care of technology-dependent children that may ameliorate the disruptive impact of the child's condition on the family; foster the child's growth and development; and transfer care to the family and community.

Effective home care is not an easily achieved goal. The physical and emotional strains of providing care for a technology-dependent child at home can be extraordinary. Stresses include the provision of care, invasion of family privacy by numerous caregivers, sleep deprivation and interruption of normal family patterns. Successful home care requires the availability of sufficient, high-quality services to families enabling them to assume the care of their child with complex medical needs at home and maintain a healthy, functioning family unit.

Studies indicate that respite care can improve family functioning and increase parent's hopefulness about a positive future and their ability to cope with a disabled child at home. For some parents, the availability of respite care may be the essential element in the decision on home care versus institutional care for their technology-dependent child. While data on the effects of respite care services upon families of disabled children is scarce, one survey on the effects of a 4-month respite care program found a positive correlation between the existence and amount of respite care and the avoidance of institutionalization. Thirty percent of participating families indicated that they would be unable to maintain their child within the home without respite services. This finding is underscored by research on the care of chronically ill adults at home. Studies have demonstrated that failure to support the caregivers in the home is the single most important determinant in their readmission to a hospital or other institution.

In testimony before the Task Force, respite care was the service most commonly requested by families and providers. Families of handicapped children rank as priorities on their list of critical needs respite from their caregiving function, time for personal/social activities, and time for spouse and other children.

Respite programs have emerged as state governments respond to the needs of specific populations, often children with developmental disabilities and/or mental retardation. Data from the Office of Human Development Services (OHD), Department of Health and Human Services, indicates that 26 states have family support programs providing respite to caregivers of developmentally disabled children. Seventeen of these programs have no age limit, other programs serve individuals up to ages 18, 21 or 24 and one state excludes children under 6 (Illinois), serving individuals ages 6—65. All but six of these state programs are established under state law.

Maine recently passed legislation with discrete funding for the provision of respite care for families with developmentally disabled children. Initially developed to serve families of children with mental retardation, the respite program of Maine's Bureau of Children with Special Needs is expanding to include families of children with autism, children with emotional disturbances and medically fragile children. This program includes a 35 hour training curriculum for respite care providers that has been accredited by the Maine Department of Education, the University of Maine and approved by the State Board of Nursing for continuing medical education. The training program is provided by the Red Cross and trainees are certified on three levels of expertise. The third level certifies registered or licensed practical nurses to provide care for children with complex medical needs.

Under grants from the OHD, three additional states have implemented demonstration projects to establish statewide respite care for families of developmentally disabled children.

Massachusetts appropriated $7.5 million in fiscal year 1988 to provide respite care for caregivers of mentally/physically handicapped children and is developing a statewide comprehensive respite care system to serve primary caregiving families of individuals with chronic, severe mental and/or physical handicaps. Under this program, the State's Task Force on Respite Care is developing a basic framework to delineate the purpose of respite care services within the state, chart a common course for agencies providing the service and create a degree of continuity throughout the respite care system.

Texas has also passed legislation to provide in-home family support, including respite care, for families of developmentally disabled children. The Texas Respite Resource Network (TRRN) has recently started a one year demonstration project at Santa Rosa Children's Hospital, San Antonio, Texas, to provide hospital-based day respite care for developmentally disabled and medically fragile children.

States can make respite care available to families of technology-dependent children under the Medicaid regular and model home and community-based waivers. However, most respite programs do not serve technology-dependent children because of their complex medical needs (TRRN's preliminary review of data from a nationwide survey would indicate that only about 10 states serve technology-dependent children in their respite programs). Despite development of respite care programs in many states, a comprehensive, integrated system for provision of and payment for respite services to meet the needs of technology-dependent children rarely exists. Services continue to be unevenly available from state-to-state, county-to-county and rural-to-urban areas. Furthermore, programs differ in definition and eligibility, depending on patient population variables. Children may often be ineligible for respite services because the provision of that service is linked to the child's eligibility for other provided service.

The foremost barrier to respite care is the general unavailability of third-party reimbursement. Reluctance on the part of third-party payers, both private and public, to recognize respite care as a necessary service seriously limits access to that service. Many states are attempting to lessen or eliminate this service gap through appropriation of funds to develop respite care programs. Available data indicates, however, that funding is unstable and families lack information about the types of care available.

Of equal importance, is the fact that most respite care programs have been developed with little or no parental input. As a result, available services do not always meet the specific needs of caregivers. A study conducted by the National Association for Retarded Citizens (ARC) in 1982 indicates that the majority of families preferred respite services in their own home. 41 percent of respite care models surveyed provided services in the home. Despite this fact, only 5.9 percent of the families had received respite care from a trained worker and 14 percent had no access to any relief. This study illustrated that families are often reluctant to use ''institutionalized'' respite services — 39 percent of the studies' sample programs reported parental reluctance to leave family members in the care of another individual. This is supported by a 1983 California study indicating that 41 percent of families served through 200 state-contracted respite care providers did not use their full allocation of respite hours and 16 percent were uncomfortable with the service. Furthermore, both studies found that a large percentage of families were unable to identify assistance or were unaware of available services.

Respite care models currently serving the developmentally disabled population include in-home programs, group homes, public or private institutional programs, local volunteer and advocacy agencies, parent cooperatives and residential camps. ARC's study indicates, however, that family relief from day-to-day care is most often provided by family member networks, with agency-recruited and trained caregivers consistently rated as second choice.

The Task Force concluded that families require funding for services, assistance in identifying respite agencies which provide quality services, and support in coping with feelings of inadequacy generated by the need for respite care. Respite care is a critical component in the appropriate care of technology-dependent children, as families may not be able to absorb the full burden of care for a technology-dependent child. Access to a responsive, flexible respite care service can ameliorate the effects of stress on the primary caregiver/family unit.

This kind of direct support strengthens the informal family caregiver system, thereby reducing the likelihood of long-term institutionalization of a technology-dependent child — avoiding costs associated with institutionalization.

RECOMMENDATIONS

- **Respite care should be included as a required component of the individualized care plan of technology-dependent children. Medicaid and other payers should include this component in the benefit package.**

- **Congress should provide funding through Title V, Maternal and Child Health block grants for development of national guidelines for respite care programs serving technology-dependent children.**

- **Congress should provide funds through the Title V, Maternal and Child Health block grant to assist states in developing and implementing respite care programs to serve children with special health needs.**

- **Congress should provide funds through the Title V, Maternal and Child Health block grant to encourage the development of volunteer networks, parent cooperatives and other self-help groups.**

- **Federal and state legislation should provide incentives to purchasers (employers, unions, etc.,) of health benefits to include respite care in their benefit packages.**

- **The Division of Maternal and Child Health should develop and dissiminate information on respite care.**

CHAPTER XI
PREVENTION

INTRODUCTION

Health promotion and the prevention of disabling conditions in children present a long-term challenge not only to the medical and scientific community but to the nation at large. Over one million children in this country have severe chronic illnesses. In addition, four million have functional disabilities and approximately 10 million children are without routine health care. The Task Force believes that the failure to prevent disabling conditions is directly related to the development of the population of technology-dependent children.

The following barriers to preventive health care for children and therein prevention of the disabling conditions of technology-dependent children have been identified.

- o Lack of adequately coordinated efforts in preventing disabling conditions and resulting technology-dependence for all children.
- o Inadequate funding of prevention activities at both state and federal levels.
- o Inadequate funding for research into the prevention of conditions leading to technology-dependence.

DISCUSSION

Improvements in overall health status of Americans over the past decades has occurred as a result of preventive measures. Targeting of medical, scientific and public resources on the eradication of infectious diseases in children has produced overwhelmingly positive results in the reduction in infant/childhood morbidity and mortality through public immunization and public health programs. This same commitment to prevention is necessary to overcome the increasing human, social and financial costs associated with birth defects, prematurity, chronic childhood illness and disabling accidents of childhood.

Every year approximately 250,000 infants are born in the United States with a birth defect. In 1985, birth defects were responsible for almost 9,000 or 23.7 percent of all infant deaths. While many birth defects are genetic in origin, most are related to maternal and parentally environmental factors. Exposure to radiation, toxic drugs, infections, alcohol and smoking have all been implicated as causes of fetal damage and/or low birth weight delivery. Low birth weight delivery is the primary cause of death in the first year of life and a leading factor in the incidence of disorders leading to technology-dependence. Aggressive neonatal intensive care of very low birth weight infants has contributed to an overall lowering of mortality while sharply increasing the numbers of ventilator-and/or other technology-dependent children in the 1980s.

Prevention activities related to technology-dependent children should occur on three levels:

- Primary prevention - avoiding the occurrence of an illness or disabling condition;
- Secondary prevention - early identification of and intervention to correct or minimize the effects of an existing condition; and
- Tertiary prevention - diminishing the impact of the illness or disability on daily life.

Primary prevention should be recognized as a primary goal in this nation's health care system. In a recent report to the President and Congress, the National Council on the Handicapped concluded that coordinated funding of prenatal and infant care initiatives could prevent a substantial percentage of the serious birth defects and illness in infants each year. The National Association for Public Health Policy has estimated that providing comprehensive, preventive oriented prenatal care is about five times more cost-effective than providing treatment oriented medical services.

Expanded funding for care of pregnant women and young children has recently been authorized under Medicaid. Approximately 25 states have expanded their Medicaid programs to include this option. Some systems provide outreach to high-risk women and successful public education of women of child-bearing age through state birth defects prevention programs. Some state systems also provide nutritional support for low-income women, infants and children (WIC); public health clinics offering a variable range of services; and public childhood immunization clinics. However, availability and quality of these services vary greatly from state-to-state.

More effective efforts in education and outreach are necessary. Although public immunization clinics exist and are universally available, approximately 25 percent of all American children under two years of age have not been fully immunized against childhood diseases whose complications may produce chronic illness and technology-dependency.

Preventive diagnostic and treatment modalities are expanding to include prenatal monitoring, potentially allowing diagnosis and correction of fetal abnormality before or immediately at birth. In severely compromised infants, it is proposed that complications of mechanical ventilation may be moderated through use of new technologies such as the high frequency ventilation and extracorporeal membrane oxygenation. Prevention of respiratory distress syndrome, the precursor of bronchopulmonary dysplasia in many infants, is currently of high priority in the area of neonatal research. This research may influence future numbers of ventilator-dependent infants and children.

Prevention programs should include activities aimed at:

- Public education on increased risks to the fetus (and individual health) of environmental factors, such as smoking, alcohol, drugs (including prescription and over-the-counter medication), environmental contaminants;
- Access and availability of prenatal care;
- Nutritional supplementation;

- Improved obstetrical and parentally services and access to those services;
- Identification of high-risk mothers and delivery of therapies to prevent premature delivery;
- Improved high-risk and low birth weight infant follow-up;
- Public education on personal safety and avoidance of accidents, poisonings and near-drownings.
- Genetic diagnostics and counselling

Various programs designed to prevent chronic disability are currently being funded through at least 45 separate Federal programs, althrough evidence suggests that there is little coordination between these programs.

Preventive services offered through the Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) program under Medicaid provides for recipients under age 21. Efforts are directed toward correction or amelioration of existing defects and chronic conditions. In Fiscal Year 1986, however, about 30 percent of all eligible children received initial or periodic examinations. Those states with active EPSDT programs are realizing cost-savings to Medicaid between 9 to 29 percent for participants over other Medicaid child recipients. This supports the Task Force's belief that prevention services will improve the general health status of children and reduce the risks of disease and/or disability. It also affirms the cost benefits of preventive care.

Development of a prevention ''checklist'' by state and federal health planners could help to identify needs and focus resources on prevention activities. The New York State Prevention Task Force has developed a checklist that represents a comprehensive and coordinated state approach to prevention activities.

Tertiary prevention for technology-dependent children encompasses an array of programmatic and individual activities discussed throughout this report. Prevention focused on diminishing the impact of a disability is critical in overcoming technical, psychological and social barriers for the child and family. Prevention activities should promote the growth and development of technology-dependent children and families and prevent further disability to these children and families.

RECOMMENDATIONS

Federal commitment to the prevention of chronic illness and disability is essential for all children and especially for technology-dependent children. This commitment should include public education, provision of preventive services to at-risk populations and continuing research on the efficacy of preventive intervention.

- **Congress should require coordination of statewide health and health-related efforts receiving Federal funds to assure efficient and effective use of resources.**

- **The Department of Health and Human Services (HHS) should sponsor a coordinated effort at a review of conditions and treatments leading to technology-dependence. The purpose of the effort would be to develop a data base whose analysis would allow the development of appropriate secondary and tertiary prevention programs.**

- **HHS should be encouraged to continue their education programs related to the health care implications of alcohol, drug and tobacco use.**

CHAPTER XII

INFORMATION

INTRODUCTION

Within the past two years, a number of studies, demonstrations, and evaluations have confirmed the viability and benefit of community-based care for technology-dependent children. Influenced by evidence from these newly completed studies, the Surgeon General opened a Conference on Family-Centered Coordinated Care for Children with Special Health Care Needs in Houston, in June 1987, with the declaration that enough knowledge, expertise and resources now exist to establish an agenda for the nation. The goal of this agenda is creation of a permanent family-centered, community-based, coordinated system of care for all children with special health care needs.

The Task Force notes that outcomes of several Title V demonstration projects illustrate the benefits of transferring technology-dependent children from institutions to the least restrictive, most appropriate setting for their development—their own homes and communities, whenever possible. Nevertheless, insufficient information exist on the design, staffing, and cordination of community-based and institutional programs to meet the individual needs of these developing children. Significant gaps also exist in the collection of data, in clinical and technological knowledge and standards, and in systematic efforts to assist families.

INFORMATION EXCHANGE

BARRIERS

- o Information related to availability of community services and sources of financial support is not readily accessible to families of technology-dependent children.

- o Dissemination of information potentially useful to parents, professionals, researchers, and public and private agencies serving technology-dependent children is fragmented at federal, state, and community levels.

- o There is a general lack of awareness on the part of the public as well as local, state, and federal health officials of the difficulties experienced by technology-dependent children and their families.

DISCUSSION

There is no central clearinghouse in the United States for information, resources, and experiences regarding long-term community-based care for technology-dependent children. Families of children with uncommon disabilities, in particular, have difficulty finding sufficient information at local libraries and community agencies. This is especially true in rural areas. The difficulty encountered in attempting to extract information from current systems was clearly evident in testimony before the Task Force.

Parents need access to various kinds of information. They need knowledge to enable them to question professionals working with their child and evaluate the effectiveness of their child's care. Health care professionals, researchers, providers, payers, policymakers, and the media all need timely, accurate information and access to expert assistance in interpreting the significance and potential costs of treatments, systems of care, and service options for families.

The Bureau of Maternal and Child Health and Resources Development (MCHRD) has been active in supporting dissemination of research and information focusing on or including technology-dependent children. Proceedings of MCHRD-sponsored conferences are regularly published and distributed through the National Center for Education in Maternal and Child Health, Washington, D.C. Several computerized single or limited-subject data bases have also been developed. For example, MCHRD and the National Institute of Mental Health (NIMH) are collaborating to better coordinate program services for chronically ill children through cross-training. This project is developing of a national database/resource directory, listing curricula, training modules, and papers pertinent to handicapped children and family services.

The U.S. Department of Education supports the National Information Center for Handicapped Children and Youth (NICHCY), an electronic information clearinghouse and network exchange that assists parents, educators, caregivers, and others in ensuring that handicapped children and youth have a better opportunity to reach their fullest potential. NICHCY is a source of information, materials, and referrals on programs, activities, and effective practices on a broad range of topics. In addition to providing technical assistance to parent and professional groups and preparing recruitment materials to encourage careers in the field, NICHCY has several publications summarizing relevant research and program information.

Several universities have begun to develop computerized systems that could evolve into national, multi-purpose, clearinghouses for information relating to technology-dependent children. For example, a National Information System for Health-Related Services (NIS) has been under development since 1984 at the University of South Carolina, under the sponsorship of the Departments of Education and Health and Human Services. The centerpiece of the System, is a computerized database of information about tertiary and specialized services for chronically and developmentally disabled children.

The NIS consists of local, state, and regional telephone and personal computer networks operated by government agencies; voluntary organizations; providers at the primary, secondary, and tertiary levels; and parents. At the University of Iowa, the National Maternal and Child Health Resource Center is conducting a variety of data collection, research, analysis, and dissemination activities to promote the improvement of health and related services for mothers and children. The Resource Center is conducting a national study, the purpose of which is to delineate future directions for services for children with special health care needs. This study will produce a multi-volume report dealing with the population in need of services, the organization of services, and their financing.

Among other database systems being developed are a computerized case management information database, at the Institute for Child Policy, in Gainesville, Florida; and a computerized patient tracking and information system, in San Diego, California, that monitors delivery of services to disabled children from Southeast Asian Families.

Collecting, updating, and publicizing timely listings of programs, publications, audiovisual and other information resources should be part of a total plan for information exchange on technology-dependent children. But much current information relating to public and private sources of financing for long-term community-based care is uncoordinated, at best. An informal survey of state Medicaid agencies conducted by the Task Force, revealed that most of the states responding did little or nothing to publicize the existence of their Section 2176 waiver programs or other Medicaid options for financing care for disabled children. Information on the array of medical assistance programs that each state finances without federal involvement has only recently been collected and published. This information is not widely distributed or publicized. Additionally, insurance plans offered through employers generally do not advertise the availability of individual case management services, even when many plans actually do cover individual case management.

RECOMMENDATIONS

- o **HHS and the Department of Education should facilitate development of an intergrated national public/private clearinghouse effort for information and referral on children with chronic illness, including technology-dependent children. This clearinghouse should take advantage of existing programs such as NICHCY, and those at several universities. The clearinghouse should;**

  1. **collect and disseminate the results of current research and demonstration studies related to the care of technology-dependent children.**

  2. **participate in setting future federal research agendas.**

  3. **sponsor an annual conference to stimulate scientific research and facilitate exchange of information useful to policymakers.**

  4. **establish criteria for selection and assist in collection of epidemiological and demographic data on technology-dependent children in cooperation, where appropriate, with other agencies.**

  5. **collect, collate, update, coordinate, and disseminate technical information on technology-dependent children and information concerning federal, state, and local programs that provide financing and/or services to technology-dependent children.**

  6. **serve as an information source for parents' groups, ombudsmen, payers, service providers, media, and the general public on matters related to technology-dependent children.**

- **To coordinate information exchange with clearinghouses and others, each state should;**

- **designate a principal point of contact and establish a toll-free telephone number to provide accurate and timely information to parents, professionals, and the public.**

- **State Medicaid agencies should make available information on Medicaid-offered financing alternatives for technology-dependent children and criteria for eligibility to all Medicaid-certified institutions in the state.**

- **The Health Care Financing Administration should continue to support regular surveys of medical assistance programs funded by individual states without Federal funds, such as the one conducted by the Intergovernmental Health Policy Project at George Washington University.**

- **Appropriate regulatory agencies should encourage employer-provided health insurance plans to advertise and describe all services covered and not covered.**

RESEARCH NEEDS

Epidemiological and Demographic

BARRIERS

- Incidence and prevalence data on the population of technology-dependent children is inadequate.

- No mechanisms exist for uniform information collection, exchange, and oversight.

- Unreliable data on total costs of care contributes to reluctance of third-party payers to expand beyond ''exception-based'' coverage for care at home.

DISCUSSION

There is no universally accepted system for defining and classifying conditions which effect handicapped children. These conditions and disabilities have traditionally been classified according to medical diagnoses. Consequently, much of the data deals with children with specific diseases or conditions. This has frustrated efforts to estimate the number of children who can be considered technology- dependent under the needs-based definition adopted by the Task Force. It also interferes with the capacity of public and private agencies to budget and plan effectively for the service needs of these children.

Lack of a uniform mechanism for information collection, exchange, and oversight impedes researchers' ability to survey the technology-dependent population nationwide as well as to conduct longitudinal studies. Reliable estimates of the population cannot be derived from existing national health survey instruments.

A Congressional effort undertaken in 1987 by the Office of Technology-Assessment (OTA) was able to estimate ranges of prevalence. Using state-based public program recipient rolls and nationwide trade group nutrition registries, OTA estimated that the number of children requiring ventilator assistance, parenteral nutrition, or prolonged intravenous drugs ranges between 2,300 and 17,000. Table 1 illustrates that the number of technology-dependent children, using a definition similar to that adopted by the Task Force, is quite small. This number could increase dramatically if the Task Force's defintion were expanded.

SUMMARY OF OTA ESTIMATES OF THE SIZE OF THE
TECHNOLOGY—DEPENDENT CHILD POPULATION, 1987

Defined population	Estimated number of children
Group I:	
Requiring ventilator assistance	680 to 2,000
Group II:	
Requiring parenteral nutrition	350 to 700
Requiring prolonged intravenous drugs	270 to 8,275
Group III:	
Requiring other device-based respiratory or nutritional support	1,000 to 6,000
Rounded subtotal (II + III)	2,300 to 17,000
Group IV:	
Requiring apnea monitoring	6,800 to 45,000
Requiring renal dialysis	1,000 to 6,000
Requiring other device-associated nursing	Unknown, perhaps 30,000 or more

SOURCE: Office of Technology Assessment, 1987.

No single reliable statistical database exists on costs of children's health care, even acute hospital care. The rarity of many childhood impairments makes it difficult to capture adequate statistics on high-cost conditions through population-based surveys.

Accumulation and evaluation of data comparing cost-effectiveness of institutional versus noninstitutional care for technology-dependent children in Medicaid Section 2176 waiver programs has been hampered by inconsistencies in state-reported data. A 1987 report by the United States General Accounting Office (GAO) characterized federal cost data collection efforts for the waiver program's first five years as ''inaccurate'' and ''inconsistent.''

Database development and data collection on the population of technology-dependent children has recently expanded. In 1986, BMCHRD sponsored publication of a Guide to National Data on Maternal and Child Health. The Guide inventories 17 national health surveys listing appropriate national source(s) of data relative. Among other data collection efforts supported by BMCHRD is the Albert Einstein Health Care Financing Project, designed to collect data on the cost of a few low-incidence chronic conditions. An effort to collect data on ventilator- dependent children is part of this project.

One new system, based on functional capacity and service needs, has been developed by the National Maternal and Child Health Resource Center, in Iowa, and is now being tested in several additional states.

All but fifteen states maintain a reporting system for children born with birth defects. These registries do not include information on all technology-dependent children. Wide variations exist in content and reliability of these systems, but they do gather information useful in identifying infants at high risk for technology- dependence. New Jersey, for example, has the oldest mandatory birth defects registry in the Nation, dating from 1926. Under New Jersey law, all families of children in the registry — those with identifiable birth defects as well as those judged to be at high-risk because of prematurity — must be offered case management and access to other services. Outreach is conducted by county-based units of the state's Title V-supported Special Child Health Services program. The registry serves as a primary source of referrals for state Medicaid model waiver programs that serve technology-dependent children.

Databases dedicated to single therapies or conditions, sponsored by commercial organizations, professional groups, or voluntary agencies, are beginning to proliferate. In June 1987, the American Association for Respiratory Care (AARC) announced development of an information and resource network for ventilator users, their families, and health care practitioners. Titled NOVA (Network of Ventilator Assistance), it will be a computerized clearinghouse linking registered families. Since 1984, the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and the Oley Foundation have sponsored OASIS, a computerized information system. OASIS has developed a registry of patients receiving special home nutritional support. Data from OASIS and commercial registries reflects the growth of home parenteral nutrition in children between 1978 and 1985, particularly among children undergoing bowel adaptation or suffering from growth failure.

In testimony before the Task Force, A.S.P.E.N. estimated that, in 1985, about 600-800 children under 18 had a primary technological dependence on enteral or parenteral nutritional support. For additional thousands, nutrition support is a secondary component to another dependence on technology, such as a ventilator or artificial organ.

RECOMMENDATIONS

- o **HHS and the Department of Education should ensure that clearinghouses establish criteria for nationally uniform selection of incidence and prevalence data on technology-dependent children and assist states in ongoing collection of information.**

- o **Congress should mandate establishment of birth defects registries, with minimum uniform data requirements, in all states. Aggregate data from all state registries should be coordinated with and made available to appropriate entities.**

- o **Professional, trade, and voluntary groups should continue to develop and expand computerized data bases and registries that include data on technology- dependent children. Data from these information systems should be coordinated with and made available to appropriate entities.**

- **BMCHRD and HCFA should collect, on a regular basis, data from state Title V and Medicaid program options which states use for technology-dependent children, including characteristics, utilization, and costs of Medicaid regular and model waiver programs. Data should be coordinated with and made available to appropriate entities.**

BIOMEDICAL

BARRIERS

- There is limited knowledge about the long-term effects of technology-dependence in children, particularly of respiratory-disabling conditions, spinal cord injuries, and conditions requiring parenteral/enteral nutrition.

- The single-disease approach to the study of childhood illness, encouraged by the organization of federally-sponsored biomedical research, deters support for studies involving comparisons of technology-dependent children with unrelated diseases.

DISCUSSION

Improvements in identification, treatment, and prevention of many disabling childhood illnesses have resulted from public and private contributions to basic research. Most of this research, which is conducted primarily in academic settings, is funded either by disease-specific voluntary organizations or by the federal government.

The National Institutes of Health—including the National Heart, Lung, and Blood Institute, and the National Institute of Child Health and Human Development (NICHD)—provide the largest share of funding for research into biomedical problems of chronic childhood illnesses. Support for research into the behavioral sciences, however, has not kept pace with funding for biomedical research. Behavioral research is critically important to families with technology-dependent children. Federal agencies that fund behavioral research relevant to chronic childhood illness include BMCHRD, NIMH, the National Institute on Disability and Rehabilitation Research, and the Office of Human Development. In recent years, funding limitations have curtailed research sponsored by these agencies, including research into service delivery and the interaction between psychosocial and physiological response to illness.

As a consequence of the single-disease character of most research, studies focusing on functional issues common to all technology-dependent children has been limited. In addition, little has been done to improve analysis of outcomes of given treatment options. Broad-based outcome measures that measure a variety of characteristics — such as activity, disease, patient and family satisfaction, comfort, achievement, resilience, and longevity — should be more widely employed by researchers.

RECOMMENDATIONS

- **Congress through the Department of Health and Human Services (HHS), should support studies designed to enhance understanding of the effects of life-support technologies on disease processes.**

- **Congress, through HHS, should support research to measure cross-disease and longitudinal outcomes for technology-dependent children.**

- **Congress should support behavioral and psychological research into adaptation by individual children to technology-dependence, including studies of families, peers, and siblings.**

ORGANIZATION AND COSTS OF CARE

BARRIER

- Policymakers, third-party payers, medical professionals, and families, do not use equivilent definitions for common terms, such as ''case management,'' ''cost-effective,'' ''benefit,'' ''risk,'' ''standard of care,'' and ''case management.''

DISCUSSION

Cost comparisons of hospital and community-based care for technology-dependent children greatly influence approval of funding, and thus, access to care at home, for technology-dependent children. Since 1981, when HHS initially waived certain Medicaid rules to permit the first hospital-bound child to receive Medicaid payment for services delivered at home, Medicaid and other third-party payers have required documentation of program cost savings as a condition for approving home and community-based services. It is not surprising, then, that most published studies focus on cost savings to Medicaid or other third-party payers. Medicaid cost savings and overall cost savings, however, are not identical. Unfortunately, few studies have attempted to document the efficiency of case-managed, community-based care versus hospital care, or to examine the benefits of care at home in the mental, emotional, and physical health and development of children.

Recent studies indicate that, for pediatric technology-dependent populations, community-based care is generally cost-effective, as compared with hospital care. Thses studies include a 1986 BMCHRD-funded survey of nine State Medicaid model waiver programs and a comprehensive HHS three-year evaluation of the entire Medicaid Section 2176 waiver program. Programs as diverse as a Medicaid model waiver program in Maryland; and community ventilator care program managed by Kaiser Permanente in Southern California; CHAMPUS'two-year home health care demonstration project; and Blue Cross-Blue Shield's individual benefits management program under its Federal Employee Program, have all reported substantial cost savings in community-based services for technology-dependent individuals as compared to hospital care. In some instances, savings in these programs have run as high as 50 percent.

Much of the mounting evidence of significant cost savings is quite recent. Surveying earlier data, the Office of Technology Assessment approached the issue of home care ''cost-effectiveness'' cautiously in its study of technology-dependent children. OTA found it impossible to define a group of children that would always be less expensively cared for at home because nursing needs and other costs of care at home differ greatly for each child.

While concluding that payers can assure themselves a high probability of cost savings only on a case-by-case basis, OTA identified some general factors that tend to increase or decrease relative costs. These include nursing costs, expected duration of dependence, family and other environmental factors, service availability, and substitution of care. OTA also recognized the effectiveness of community-based services — particularly case management and respite care — in increasing the quality of care and of life and reducing rehospitalizations for these children.

RECOMMENDATIONS

- **HHS should include children and young adults in any future studies and demonstrations of catastrophic insurance coverage.**
- **HHS should initiate longitudinal studies to investigate the medical and psychological impacts and financial costs of long term care in a variety of alternative care settings.**
- **HHS should review past experiences of national programs devoted to groups of technology-dependent individuals — such as ESRD and hemophilia — as well as foreign programs involving complex medical technology, to identify potential innovations and savings in programs for technology-dependent children.**

FAMILY SUPPORT

BARRIERS

- There is insufficient information on factors influencing family adaptation to care at home for their technology-dependent child and the role of an organized service program in effecting successful family adaptation.
- There is limited knowledge on long-term outcomes of community-based care relative to the development and well-being of children and families.
- There is little understanding of the impact of differing treatments or interventions on technology-dependent children and their families at different stages of child and family development.

DISCUSSION

The chronic nature of the care of technology-dependent children at home places tremendous physical, financial, and social burdens on families. While the family's key role in caring for the technology-dependent child is evident, the full dimensions of this role have yet to be explored.

Because studied populations have been small, much of the existing knowledge about the family as caregiver is based on anecdotal information. Academic research with families has used primarily qualitative analysis. It has focused the burdens on families or the effectiveness of certain interventions in helping families cope. One recent study identified sources of stress for mothers of medically fragile children as finances fatigue, time and schedule demands, and social isolation. Resources identified as most helpful in improving the mother's ability to cope included help from nurses and other family members, and sense of commitment.

At present, gaps in information impede understanding of the family as primary caregiver. These gaps include identification of the motivating factors empowering family members to assume and manage a primary caregiver and/or case management role and those factors that deter families from assuming this role. Research should focus on strategies for coping and identification of the kinds of information, education, and support that develop and reinforce the coping abilities of families. It should also focus on successful family characteristics and interaction patterns that appear most vulnerable to breakdown. Contributions of all members of the family unit should be considered, including the child and siblings. In addition, the relationship between long-term custodial arrangements and appropriate growth and development in technology-dependent children deserves study. Finally, evaluation of the impact of innovative alternative care settings and social support systems for those children not receiving care in their own homes is needed.

RECOMMENDATIONS

- **BMCHRD should fund studies to examine family variables as they relate to the delivery of care in the family home.**

- **BMCHRD should fund studies to assess the impact of long-term dependency on mechanical life support devices on the technology-dependent child's relationships with his/her family and nonfamily care providers.**

- **HHS should support demonstrations of small group homes and foster and adoptive care placements for children unable to receive care in family homes.**

- **BMCHRD should support studies exploring the long-term behavioral and psychological impact on the child and family of different components of treatment.**

- **HHS should continue support for demonstration projects of alternative care options, including respite care, medical day care, and summer camp, evaluating the relationship between availability and use of these alternatives and successful home care.**

CHAPTER XIII

FINANCIAL

Introduction

Care of technology-dependent children is costly in any setting. Unless relieved by private or public insurance, public funding, or private philanthropy and charity care, the cost of providing appropriate care for this small population of children is beyond the means of all but the wealthiest families.

In contrast to the relatively generous private and public financing for institutional services, support for family care and community- based residential arrangements is limited. Many of the services most needed by technology-dependent children are not routinely reimbursed by either private health insurance plans or by Medicaid and other public third-party payers.

Most current community-based care is delivered under ''exceptions'' to normal reimbursement policies and approved only in cases in which the payer is assured of cost savings. These ''exception-based'' policies are a pragmatic response to the lack of an overall national approach to coverage of chronic conditions. They are administratively cumbersome, variable, and heavily reliant on public welfare eligibility criteria that were not designed to consider a family's expenditures along with its income in determining eligibility.

The degree to which a technology-dependent children has access to adequate financing for appropriate health care depends upon the extent to which the child is covered by private insurance or public health care financing programs. The extent and adequacy of private insurance in covering costs associated with the care of technology-dependent children in the hospital and at home and the extent of public payment for home services from all available sources are examined fully in Appendix C, ''Sources of Financing.''

This chapter explores deficiencies in private and publicly-financed health benefits programs in covering care of technology-dependent children, particularly in home settings. It identifies specific financial policies and practices that bar access to needed services for these children in private health insurance and in Medicaid and other public programs. It sets forth Task Force goals in developing recommendations for removal of these barriers.

Access to Financing

Barriers

- o There is inadequate access to financing for appropriate care.
- o Incentives for cost-efficient care are lacking.

- The apportionment of family financial responsibility is inequitable.
- The design and coordination of benefits is inflexible.
- Payment limits are inadequate.
- Incentives to assure high quality care are inadequate.
- There is insufficient support to help families locate and secure access to financial resources.

Discussion

The deliberations of the Task Force reflect a general consensus about the nature of the barriers to appropriate care. The overriding barrier is lack of access to adequate home and community-based care. Both private and publicly-subsidized health insurance programs are biased toward hospital care and physician services. The lack of reimbursement for the whole range of services appropriate for the child receiving care at home shifts the burden of financial responsibility heavily toward the family. As a consequence, technology-dependent children and their families are frequently trapped into extended hospital stays in order to remain eligible for third-party insurance coverage. This may occur even when it can be demonstrated that noninstitutional care is less expensive than the comparable level of institutional care.

Few current financing arrangements are flexible enough to pay for adequate nursing and non-physician professional care; other needed supports, such as home adaptation and transportation; and family supportive services,including respite care. Fewer payment mechanisms are set up to recognize the needs of each technology-dependent child. Unless care plans are individualized and services properly coordinated, rather than based on fee schedules or capitation, care providers may not be encouraged to take as much time as required to ensure the high level of quality critical to successful care of these children.

In formulating its recommendations, the Task Force has agreed that its major proposals for financing appropriate care should address the following: (1) universal access. (2) cost- efficient care. (3) equitable family financial responsibility. (4) family representation in care management. (5) creative delivery of services to facilitate habilitative capability of the child. (6) public-private third-party cooperation. (7) assurance of high quality care. (8) assurance of service capacity on the local level.

By universal access, the Task Force is not endorsing cost-free publicly-subsidized care for all technology-dependent children. The Task Force strongly supports preservation of the private sector's role as payer of first resort for the majority of children with an employed parent. In this regard, a combination of federal and state mandates and incentives to expand the number of privately insured families and to improve the adequacy of health insurance benefits is necessary and desirable. Private insurers should be prevented from withdrawing from or reducing current commitments to technology-dependent children.

At the same time, some technology-dependent children have no private sources of health care financing. For these uninsured and underinsured children, ongoing access to publicly-supported financing programs is essential. Access to publicly-financed third-party reimbursement sources, especially Medicaid, needs to be broadened for families with expenses beyond a ''catastrophic'' proportion of their income.

Systems of Excellence

The Task Force has designed a model service delivery system for technology-dependent children. This service model links financing to community-based case management organizations which are federally qualified and monitored, but state certified which are called systems of excellence. These organizations would plan and manage individualized services and benefits for technology-dependent children.

The concept calls for the systems of excellence to arrange delivery of medical, developmental, and supportive services provided to a particular technology- dependent child for a flat fee. This fee would reflect the community's capability to provide the care and include the systems' administrative costs, including stop-loss insurance, as well as the amount used to purchase the services. The systems of excellence would be at-risk financially to stay within the amount negotiated with the payer for a child's care during a specified period of time.

The systems of excellence would appressively pursue collection of funds from all liable third-party payers, including responsible public and private agencies. Reasonable family financial participation in the care delivered to technology-dependent children by the systems of excellence would be required. Medicaid would remain payer of last resort.

Principal responsibility for the administration of the systems of excellence would be at the state level. The Department of Health and Human Services would develop broad criteria for state systems of excellence. These criteria are expected to rely heavily upon the recent Title V program experience with this population. States would be able to promulgate their own standards for the systems consistent with the federal criteria.

The systems of excellence concept is adaptable to both public and private approaches to financing care. The major objective of the concept is the provision of comprehensive, coordinated care of the highest possible quality for technology-dependent children in the most cost-efficient manner.

Approaches To Providing And Financing Services

The Task Force is recommending three specific approaches to the provision and financing of health care services for technology-dependent children. Two of the approaches would provide comprehensive reforms in the provision and financing of services. One such approach would utilize the federal-state Medicaid program to assume administrative responsibility and coordinate care for all technology-dependent children. The other such approach would involve a combination of private payments through family-paid premiums and public funding of a consortium of private health insurance companies which would develop and administer a system of care for technology-dependent children.

The third approach, which will be discussed first in this chapter, recommends a series of incremental policy changes which make maximum use of existing programs and expertise to redesign benefits to better finance care for technology-dependent children. There was clear agreement among Task Force members that one of the approaches should include recommendations for improvements in the existing provision and financing of services. The Task Force recommends that the Medicaid-sponsored approach be considered as a first priority for implementation. The public privately administered health insurance consortium should be implemented as a demonstration.

Financing Selected Incremental Policy Changes

This approach addresses elements in existing public and private health insurance policies and practices that limit opportunities for service in community settings. Unlike the two following approaches which would restructure the way services to technology-dependent children are organized and financed, this approach contains proposals to overcome some specific barriers to appropriate care in the design of current programs. These proposals are responsive to barriers identified and other concerns raised by numerous witnesses before the Task Force.

The advantage of these recommendations for incremental change is that each can be carried out independently to make current systems more responsive to individual needs. The major disadvantage is that adoption of these recommendations will not assure that the principle of universal access to appropriate care for technology-dependent children will be achieved.

Barrier

- There is a lack of universal access to financing for appropriate care for families with technology-dependent children.

Discussion

A coordinated state-level system able to mesh private sector insurance products with federal programs and state initiatives including private insurance regulation must exist to assure universal access to health insurance for technology-dependent children. States should establish a single coordinating office for technology-dependent children and funding programs that assist their families.

Recommendations

- **Congress should establish the principle of universal access to appropriate care for technology-dependent children.**

- **Congress should require states to establish plans and timetables for achieving conformity with this principle.**

Barrier

- o Some insurance product benefit designs are inadequate to meet the needs of technology-dependent children and some insurance companies are unresponsive to the needs of such families.

Discussion

Testimony was presented to the Task Force concerning barriers to effective care which exist in the current private insurance system. These barriers were perceived to derive from multiple sources, principally from benefit designs that are inadequate to meet the needs of families with technology-dependent children and attitudes of insurers that are unresponsive to these needs. The extent and nature of the barriers varied among states and among insurance programs.

Recommendations

- o **Each state insurance regulator should take steps to assure that the private insurance industry is responsive to the needs of families with technology-dependent children.**

Such steps should include:

1. **Assuring that insurance rates are not discriminatory and are reasonably related to the actual costs of delivering benefits to the insured population.**

2. **Promoting the availability of full-benefit insurance products at discounted prices for low-income families.**

3. **Requiring waiting periods on pre-existing conditions no longer than six months.**

4. **Requiring health insurers to include case management services at no extra charge to families with technology-dependent children.**

5. **Encouraging insurers to offer structured settlements in the form of medical trusts for the care of technology-dependent children.**

Barriers

- o Many health insurance policies exclude coverage for maternal and prenatal care.

- o Some insurance programs exclude benefits for newborn infants.

- o Some insurance benefit programs do not include coverage for in-home care.

- o Many health insurance policies do not include coverage for respite care.

- o Durable medical equipment is inadequately covered in many health insurance policies.

Discussion

The Task Force reviewed material and testimony which demonstrated the importance of maternal and prenatal care to the full-term, healthy delivery of infants. Extreme prematurity and extreme low birth weights are associated with the need for technology in infant care.

Approximately twenty states currently require that maternal and prenatal care be included as benefits in some or all health insurance policies sold in their state. The contribution of such benefits is sufficient to warrant legislative and regulatory mandates to include them in all family insurance policies sold in every state. Further, all health insurance policies designed for individual subscribers should also include maternal and prenatal care benefits that can be declined by individuals if they choose.

Self-insurance programs are exempt under the Employee Retirement Income Security Act (ERISA) from such legislative mandates and state regulations. Therefore, it is permissible for self-insured employers to exclude newborn coverage from their benefit plans. Congress needs to close the loophole which permits self-insured employers to escape minimum benefit mandates related to the provision of care to newborn infants.

Purchasers and users of health care have historically been most concerned about the high costs of hospitalization and the need to insure themselves against the costs for hospital care and related professional services. Ambulatory care benefits are more recent additions to benefit packages. The development of in-home treatment options, especially for medically fragile children has progressed at a pace faster than the design of insurance products. Both insurers and group insurance purchasers have historically resisted providing in-home care benefits because of the perception that they would be cost-inflationary. The increased use of outpatient treatment as a cost-containing alternative to hospitalization should lead insurers and purchasers to support in-home care to the extent that it is a replacement for more expensive care.

The financing of respite care is a source of longstanding concern to insurers and purchasers of insurance. The key challenge is to structure a benefit program so that the respite care benefit is available to those families where it is truly needed and where it is cost-neutral or cost-saving.

Barriers involving durable medical equipment have multiple components. Witnesses before the Task Force cited problems resulting from lack of coverage for durable medical equipment, from lack of coverage for back-up equipment and from lack of coverage for equipment maintenance.

Recommendations

- **Employers should offer and employees should seek health benefit programs which consist of the following benefit provisions for family coverage: (1) maximum lifetime benefits of at least $1 million; (2) maternal and prenatal care; (3) coverage of children from birth; (4) case management services; (5) in-home care; (6) respite care; and (7) durable medical equipment. Individuals who purchase family health insurance benefits directly from insurers should obtain benefits consistent with those recommended above for employees.**

- **Each state insurance regulator should take affirmative steps to ensure that insurers include within their family health insurance policies coverage for the following individual benefits: (1) maternal and prenatal care; (2) children from birth; (3) in-home care; (4) respite care; and (5) durable medical equipment, including provision and maintenance of primary and back-up equipment.**

- **Congress should permit exceptions to ERISA so that self-insured plans and multi-employer trusts can be obligated to cover maternal and prenatal care and children from birth in all health insurance policies.**

- **Congress should grant unincorporated businesses and self-employed persons full tax deductibility for contributions they make to employee health benefit plans containing at least the benefits recommended above for employees.**

- **Congress should continue the legislative mandate enacted in the Consolidated Omnibus Budget Reconciliation Act of 1985 requiring employers to offer continuation-of-benefit programs.**

Barrier

- There are inadequate levels of support and coverage for technology-dependent children in state Medicaid programs.

- Some low-income families slightly above income eligibility limits are denied access to Medicaid.

Discussion

Task Force members have consistently called for uniform Medicaid eligibility standards in each state. Medicaid-eligible technology-dependent children should have equal opportunities for access to appropriate care regardless of their state of residence. HCFA and the states should recognize that the current Section 2176 waiver program is a cumbersome and uncertain administrative mechanism. While the best state waiver programs are successfull addressing coordinated care for this small group, after five years some states have not opted to develop waiver programs or any other viable state-supported options for technology-dependent children. The Task Force is also concerned that states have shown little or no enthusiasm for some Medicaid coverage options recently authorized by the Congress. For example, in-home respiratory care services for ventilator-dependent individuals could serve some children in home and community settings without waivers. OBRA of 1986 made this option available to states. Yet, no state has chosen to adopt it.

The Task Force heard several specific suggestions that it can recommend to target Medicaid resources more effectively for families with technology-dependent children. First, states should establish an administrative capability dedicated to meeting the needs of this population. Fiscal planning, program development, and service coordination activities should be undertaken that are designed to ensure that a child's individual service needs are met. The program could be set up through the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. Every state must provide EPSDT services to Medicaid-eligible children. For a child assessed and diagnosed under EPSDT, a state may fund as treatment any service authorized by the federal Medicaid statute, regardless of whether it offers the service under its state plan.

Second, states should be encouraged to set up targeted "buy-in" programs for families of technology-dependent children. Under current law if a technology-dependent child is living at home and the family's income is above the state's standard of need, the family may incur serious financial liability. This may involve substantial cost-sharing in the states with a Medicaid spend-down program or ineligibility in states without a Medicaid medically needy program. A buy-in program would enable families with incomes above Medicaid eligibility limits, but below 200 percent of the federal poverty level, to buy Medicaid benefits as they would buy a private insurance policy. Premiums could be imposed, up to a maximum of 10 percent of annual family income. Reasonable deductibles and copayments could also be imposed.

Recommendations

- **State Medicaid programs should work to meet the special needs of families with technology-dependent children by:**

  1 **Establishing an administrative capability to assist families with technology-dependent children to coordinate payment sources and to use available services effectively.**

  2 **Identifying potentially eligible technology-dependent children, so that they can be provided with targeted case management services.**

  3 **Providing targeted case management services, authorized by the Consolidated Omnibus Budget Reconciliation Act of 1985 to coordinate appropriate care for families of all potentially eligible technology-dependent children.**

- **In order to provide adequate incentives for states to meet the special needs of technology-dependent children and their families, Congress should authorize federal Medicaid matching funds at a 90 percent level.**

- **To further encourage states to provide home and community based services to technology-dependent children. Congress should remove all existing waiver requirements, making this coverage a state optional service.**

- **To cover uninsured and underinsured children who are technology-dependent, Congress should authorize and states should undertake programs which allow families with incomes above state standards of need to "buy-in" to Medicaid. Families with incomes above Medicaid eligibility limits, but below 200 percent of the federal poverty level should be eligible to buy Medicaid benefits, including home and community-based services. Premiums could be imposed, up to a maximum of 10 percent of annual family income. Reasonable deductibles and copayments could also be imposed.**

- **Congress should direct the Department of Health and Human Services to investigate the use by states of Medicaid legislative options that can serve technology-dependent children — including Section 2176 regular and model waivers, TEFRA Section 134 state plan amendments, and EPSDT — to determine what additional measures are needed to induce more states' capacity to provide appropriate care for technology-dependent children.**

Barrier

- o States have an inadequate commitment to maternal and prenatal care for low-income women.

Discussion

Opportunities exist through recently-enacted Medicaid legislation for states to expand significantly their maternal and prenatal care services to low-income pregnant women who are at higher risk of bearing a low birth-weight baby. Currently, only 27 states have taken advantage of this legislation. The Institute of Medicine estimates that for every dollar spent on prenatal care, more than $3 may be saved on care for underweight newborns. The problem of low birth-weight babies is significantly associated with teenage pregnancies. Special program efforts targeted at this population of young mothers-to-be should be undertaken.

Recommendations

- o **Congress should endorse and fund the Maternal and Child Health program, the Women, Infants, and Children program, and teenage pregnancy programs aimed at preventing low birth-weight babies.**

- o **States should expand their efforts to promote the birth of healthy babies by:**

  1 **Establishing, at a minimum, Medicaid eligibility for pregnant women and children up to age 22 with incomes up to 200 percent of the federal poverty level. All States should be mandated to develop timetables for doing so.**

  2 **Maximizing their participation in the federal Maternal and Child Health Program and the Women, Infants and Children program by augmenting these programs with state-funded initiatives.**

  3 **Undertaking programs to reduce teenage pregnancy.**

Medicaid-Sponsored Financing Plan

Under this approach, which the Task Force chose as its preferred approach each state Medicaid agency through its Early and Periodic Screening, Diagnosis and Treatment (EPSDT) service authority (and in consultation with the state's Title V program), would arrange for delivery of ''appropriate care'' as specified in an individual care plan by a state-certified organization.

The Medicaid agency would negotiate an individualized prepaid fee with the system of excellence for coordination and delivery of a particular child's care for a defined period of time. This fee would reflect the system's administrative costs (including stop-loss insurance), as well as amounts used to purchase services. The system would be flexible to accommodate unanticipated events, such as re-hospitalization or the need for services not in the originally-negotiated package.

Prospective funding under this approach would be the responsibility of state Medicaid agencies. The Medicaid agency would aggressively pursue collection from other liable third-party payers to offset Medicaid costs. Reasonable family contributions would also be collected.

This approach makes Medicaid administratively responsible for providing access to systematically coordinated care for all technology-dependent children, without regard to their financial eligibility.

Medicaid was chosen because of its preeminence in health care financing matters at the state level. This choice also assures a continued federal role in quality control. In addition, Medicaid's primary administrative role recognizes that under current Supplemental Security Income and Medicaid rules, payment for these children's care becomes a Medicaid responsibility after other sources of third-party payment are exhausted.

The Medicaid EPSDT service authority was chosen, under this approach as the financial and administrative point of access within each state to coordinated multi-source financing and services for technology-dependent children. This is because EPSDT is already a mandatory service under each state's regular Medicaid program. No major new federal legislation is needed to enable states to target special services to an individual child, based on diagnosis. Medicaid regulations permit state Medicaid agencies to provide a child under EPSDT with health care, treatment, and other measures recognized in Medicaid law and regulations, including home and community-based services to correct and ameliorate any defects and chronic conditions discovered through screening.

Medicaid would remain the payer of last resort under this approach. Even though Medicaid would pay for the services of a contracting organization on a prospective basis, the Medicaid agency would be authorized to assess and collect from each responsible third-party payer contributions up to the limits of that payer's liability for a particular child, as well as reasonable contributions from the child's family, premiums could be imposed up to 10% of annual family income. Retention of Medicaid as the payer of last resort would continue. Private and public third-party payers in the system would be encouraged to continue their participation.

This approach meets the Task Force goal of developing a system of family-centered, community-based, coordinated care without significant new federal legislation. New legislation would be required only to:

- Waive Medicaid eligibility requirements to run the program through the existing EPSDT statutory mandate.

- Waive freedom-of-choice, through Section 1915 (b) of the Social Security Act, to permit all states to negotiate prepaid flat per-child Medicaid payments with qualified organizations.

- Waive family responsibility prohibitions in Title XIX (Medicaid) to permit greater than ''nominal'' family financial participation in costs of care for technology-dependent children.

Public-Private Consortium Administered Financing

This approach is designed to finance and coordinate all technology-dependent children covered by this plan and the premium rates would actuarially take into account that certain of these children would also be covered by private insurance and other plans. The consortium would be responsible for seeing that these plans paid first, just like in a primary/secondary determination on coordination of benefits, as well as subrogation against casualty insurance benefits. It is also for those who have exceeded their benefit limits under their private health plan or a public program such as Medicaid. The Task Force felt strongly that this approach should be implemented as a demonstration project.

Under this approach, development and administration of a system of care for technology-dependent children with inadequately or no coverage would be the responsibility of a independent carrier or a consortium of private health insurance companies. Membership in the consortium would be determined through a bidding process conducted by the Department of Health and Human Services. HHS would also be responsible for assuring fiscal responsibility of the services carrier or consortium and providing quality assurance for the care rendered.

A technology-dependent child would be identified through state and local government procedures or by a hospital. When program eligibility is established, the services carrier or consortium would price the risk, determine specific benefits, develop the provider network, and arrange for service delivery which utilizes a coordinated and case-managed approach.

Congress would have to establish financing through a risk fund for the program with an initial endowment grant. Federal funds would also be required to subsidize the costly annual premiums paid by the children's families. This approach is modeled as a single-premium ''substandard'' major medical contract for a time certain (i.e. three years). Underwriting highly ''substandard'' (in this case generally uninsurable) risks is a new area for insurers. Such a contract is possible, but is considered highly risky without risk diminishing safeguards such as reinsurance.

The major medical contract would offer several advantages, if adopted, to finance the care of technology-dependent children. The carrier or consortium would receive payment on a prepaid basis for a time certain (i.e. three years) which would permit investment earnings and thereby reduce costs. The carrier or the consortium would be responsible for paying the claims for the child's care and managing the child's care.

Strong safeguards for fiscal responsibility would need to be incorporated into the consortium's design. A major drawback is the lack of insurers' experience with the single-premium ''substandard'' major medical contract. Nevertheless, some large carriers have expressed interest in joining this type of plan.

This approach would not eliminate all third party payors but would simply be a gap filler to assure the technology-dependent child receives a scope of benfits to be provided to all technology-dependent children. However, it encourages private third-party payers to become members of the services carrier and financing consortium for technology-dependent children. A Task Force goal of maximizing private and public cooperation in providing community-based, coordinated care to technology-dependent children is met through this approach which builds on the model of the single premium ''substandard'' major medical concept.

The following outline summarizes how this joint program between the federal government and private insurers would work to provide funding and manage care for technology-dependent children:

1. Technology-dependent children would be medically classified in one of four levels of care in order to make proper initial funding estimates. Such a procedure would not mean that children would be treated differently but merely that their level of care would be more or less costly. For example, the three year cost of caring for a child in one group might be $100,000 while it is $400,000 for a child in another group.

2. Because it is desirable to have more than one insurer involved in the program to avoid having the federal government set up a private industry monopoly and to truly test this program, the country could be split into four sections. This geographic division could be Northeast, Southeast, Northwest, and Southwest.

3. An insurer wishing to administer the program in a region would prepare a bid including an estimate of the expected claims amount per child and administrative costs for processing claims and case management. The bid would also take into account investment income that could be earned. Investment income would accrue on the money the insurer receives from the risk fund each time a child becomes eligible under their program. The insurer would receive a single payment designed to cover costs from the date a child enters their program until the end of the three year contract period. Prorated payments would be made for children entering an insurer's program at times other than the beginning of the fixed three year contract period.

4. The insurer would invest payments received from the risk fund so money would be available to pay claims as they occur. The insurer would also have responsibility for managing the care of each child in its program, paying for care through appropriate claims administration, establishing proper administration to keep whatever other insurance is available on any child in force, and keeping appropriate records and making appropriate reports.

5. A reinsurance mechanism would provide a cap in the case of an unexpectedly high level of claims. If a child's care estimated to cost $100,000 actually cost $200,000, then the reinsurer would pay all costs beyond that point. The original insurer would continue to function in its normal capacity, but would simply recover the excess claims payments from the reinsurer.

6. It would probably be most appropriate for a single organization to be the financial intermediary receiving the single payment per eligible child from the risk fund and disbursing it to the regional insurers as needed. If regional insurers show a profit from their investments for the three year contract period beyond some specified level, then those extra monies would revert back to the risk fund which could be managed by a single financial manager or representatives of all the regional insurers.

7. Variance from expected claims levels would create a profit or loss for the insurer. Losses would be capped, but not eliminated through the reinsurance process. Profits would occur from lower than expected expenses and recoveries from other types of insurance.

8. A delayed eligibility cycle would be expected when the program starts operating due to eligible children being identified gradually. The program should be operating smoothly by the time the second three year contract period begins. Insurers would also be expected to receive more full three year premium payments and fewer prorated payments for the second contract period.

Financing Program Development Activities

The need to continue to build service capacity and expand information and networking activities at the state and local levels that will benefit technology-dependent children and their families was a major theme in Task Force testimony. To accomplish this requires the expertise at the Federal level that has been demonstrated by the Title V program in its ongoing encouragement of community-based care for these children. At the state level, a strong interrelationship between Title V and Medicaid has been shown to be an important factor in the success of the best Section 2176 waiver programs.

State Title V agencies would have major responsibilities for administering the program development and capacity-building activities described in the previous section. This would be in addition to monitoring and surveillance responsibility in the quality assurance program for technology-dependent children, as proposed by the Task Force. Title V agencies' experience with in community outreach, education, and case management programs strengthens their capacity to respond to new program needs.

Title V responsibilities at the Federal level would include leadership, education and coordination; maximization of resources; direction of program; development grant programs; development of criteria and statdards for ''systems of excellence,'' as proposed by the Task Force; development of quality assurance mechanisms; continuing identification of new issues; maintenance of linkages with education and social services agencies on policy issues, (such as P.L. 99-475); and coordination with the Surgeon General's agenda for children with special health care needs.

Most care coordination, service support, and information and networking activities that the Task Force proposes be undertaken by Title V agencies in support of technology-dependent children can be carried out under Title V's existing legislative authority, continuing to rely on existing financing strategies. New Federal Title V funding would be needed only to conduct a direct capacity-building grant program, anticipated to operate for a 3-5 year period. The program development issues which would be addressed under this grant program are crucial to closing gaps in current information identified by the Task Force. Among them are, (1) technology/standards/safety/monitoring of in-home equipment, (2) para-professional caregivers, (3) schools/education, (4) social service needs/alternative living options, and (5) long-term research-outcomes study.

CHAPTER XIV

CIVILIAN HEALTH AND MEDICAL PROGRAM OF THE UNIFORMED SERVICES

(CHAMPUS)

This chapter includes separate recommendations for overcoming barriers to community-based services within the CHAMPUS program. CHAMPUS shares many of the characteristics of a private insurer, except that like other publicly-financed programs, Congress has direct jurisdiction over its policy and program design.

Barriers

- The policy interpretation of ''custodial care'', is exclusionary.
- There is inadequate coordination of military and community financing resources.
- The $1,000 limit on monthly Program for the Handicapped benefits is inadequate.
- The ''level-of-care'' eligibility requirments for CHAMPUS' home care demonstration are limited.

Discussion

Witnesses before the Task Force and other sources emphasized the difficulty and frustration of securing CHAMPUS reimbursement for care of technology-dependent children in military families. Their experiences made a deep impression upon the Task Force.

Military families of technology-dependent children face unique challenges in obtaining nonhospital long term health care within the military health care system. There are no military health care institutions other than hospitals. All nonhospital care must be provided in the community and reimbursed by CHAMPUS. In paying for health care not available in military treatment facilities, CHAMPUS operates similarly to private health benefit plans. Unlike private insurance, however, CHAMPUS benefits are subject to direct Congressional control.

By Department of Defense (DOD) regulation, neither CHAMPUS nor military treatment facilities may provide, or pay for, ''custodial care''. CHAMPUS provides generous home health benefits. These Benefits are only available, however, to patients determined to need an acute hospital level-of-care. As currently interpreted by CHAMPUS and most military hospitals, this regulation precludes provision of, or payment for, most of the services and supplies associated with long term care for technology-dependent children.

CHAMPUS's policy manual defines ''custodial care'' as care rendered to a patient:

1. who is mentally or physically disabled and such disability is expected to continue and be prolonged;

2. who requires a protected, monitored and/or controlled environment whether in an institution or in the home;

3. who requires assistance to support the essentials of daily living;

4. who is not under active and specific medical, surgical, and/or psychiatric treatment which will reduce the disability to the extent necessary to enable the patient to function outside the protected, monitored and/or controlled environment.

Technology-dependent children fall into DOD's ''custodial'' category if their long-term needs for assistance and a monitored environment are unlikely to be reduced through active treatment. Military children determined ''custodial'' may receive only limited CHAMPUS home health benefits for the custodial care condition — prescription medications, medical supplies, and nursing care of up to one hour per day, or they may utilize the Program for the Handicapped.

Under current regulations, payment under CHAMPUS is excluded even for inpatient hospital treatment of the chronic condition for which custodial care is being received. This policy is currently being revised. A DOD-proposed rule to amend this exclusion would allow payment of inpatient hospital care that is determined medically necessary, even if required for a custodial condition. In practice, some military hospitals now care for technology-dependent children considered ''custodial'' for extended periods of time. Once the hospital chooses to discharge the child, however, the child's family must seek other financial support for needed care in the local area.

To deal with the complexities of funding, military families have an especially critical need for skillful case management. The child's home and community-based care needs can be met only through coordination of multiple military and civilian health, education, and social services. The family's ability to achieve sufficient financing for their child's appropriate care in the community depends upon the particular mix of resources available to them in their area. Many military families are not eligible for Medicaid because of income limits or other program restrictions in some states. This reduces the potential for adequate funding for community-based care to the level available to non-military families. Exclusion from Medicaid for these families can be offset, within limits, by funding through the Program for the Handicapped, which is not available to the civilian population.

Technology-dependent children who are dependents of active duty military personnel can receive some assistance for community-based care through CHAMPUS' Program for the Handicapped (PFTH). The PFTH was established by Congress to provide financial assistance to active duty members' seriously mentally or physically handicapped family members when the required medical services are not available from public programs or institutions. PFTH benefits include diagnostic services, rehabilitation, training, special education, durable medical equipment and supplies, and certain transportation. The PFTH covers institutional, outpatient, and home care, including daily skilled nursing care in the home. All services covered under the program must be preauthorized.

Combined with the supplies and equipment covered under the CHAMPUS Basic Program, the PFTH could be a primary source of assistance in the community for technology-dependent children in military families. Current law, however, prohibits combining PFTH benefits with CHAMPUS Basic Program benefits. Another major barrier in the PFTH is its current legislatively-imposed $1,000 maximum monthly benefit limit. This limit is inadequate to cover initial equipment and nursing costs typically generated in the care of a technology-dependent child. However, once initial costs are covered, the PFTH in coordination with other available and appropriate resources generally provides adequate resources to fund the skilled care required by technology-dependent children.

The Task Force is encouraged that, over the past year, DOD and Congress have recognized the need for protection against catastrophic out-of-pocket expenses. Congress recently enacted a catastrophic protection provision (Sec. 721 of the 1988 Defense Authorization Act, P.L. 100-180), which limits annual out-of-pocket health care expenses under CHAMPUS' Basic Program (but not the PFTH) for active duty military dependents and their families to $1,000.

Enactment of catastrophic protection in CHAMPUS' Basic Program underscores the need for additional funding flexibility to insure full access to home care for all technology-dependent children of military personnel.

To address current gaps in services for military families, on July 1, 1986, CHAMPUS began a two-year demonstration of home health care for family members of active duty personnel. Under this demonstration, extensive medically necessary, appropriate, and cost-effective home health care services can be offered to patients who would otherwise be receiving hospital care. These services may include skilled daily nursing care, home health aides, therapies, and related services to support family-centered, coordinated, community-based care.

Through 1987, a total of 58 requests for the home care demonstration project had been received, the majority for technology-dependent children. Only about half of these were approved. Those disapproved did not meet the CHAMPUS requirement that demonstration participants need a hospital level-of-care. However, alternative home care benefits were offered under the CHAMPUS Basic Program or the PFTH for those disqualified. Additionally, the parents of technology-dependent children were assisted with locating those personnel and resources available to the civilian population.

Results of the current CHAMPUS home health demonstration reflect individual cost savings of up to 45 percent compared to hospitalization. A provision in the Defense Appropriations Act of 1988 continues this demonstration and expands it on a limited geographic basis to provide comprehensive, individualized case management for patients with exceptionally serious, long-range, costly and incapacitating physical or mental conditions. Considering the excellent leadership for the demonstration already provided by CHAMPUS and the program's success to date in substituting cost-effective, appropriate community-based care for hospital care, the Task Force believes that the major objectives of the demonstration could be enhanced.

Broadening eligibility for the demonstration to include all military dependents meeting the Task Force's definition of technology-dependent would give these children the same access to coverage through their primary payer — CHAMPUS — as the Task Force is recommending for technology-dependent children covered by private health benefit plans. Initiating such coverage through the demonstration would maximize CHAMPUS' capacity to evaluate results of systematic individualized care planning for these children.

Recommendations

- **DOD should expand its current policy review of "custodial care" to include increasing the military health care system's flexibility to finance family-centered, coordinated care in the community for technology-dependent children**

- **To assist military families of technology-dependent children, DOD should contribute to and participate in an information and referral database that would:**

  1. **Make possible early identification and comprehensive planning;**

  2. **Support families in gaining access to resources within the military community and/or appropriate local, state, and federal civilian sources of care and assistance;**

  3. **Coordinate information resources with information clearinghouses serving the needs of technology-dependent children.**

- **Congress should raise the current $1,000 PFTH limit for community-based services to remove current financial incentives for institutionalization.**

- **Congress should change the regulation, policy, and operation of the PFTH to remove the current restriction on the dual use of the PFTH and the CHAMPUS Basic Program.**

- **In extending CHAMPUS' home care demonstration, Congress should broaden eligibility to include all technology-dependent military dependents meeting the Task Force's definition.**

APPENDIX A

DEFINITIONS

Definitions were developed by the Task Force in order to facilitate an understanding of issues and terminology related to technology-dependent children

Technology-dependent

In general use, the term ''technology-dependent'' is non-specific. It may include technology providing life support to items such as hearing aides, glasses, and wheelchairs. The definition of ''technology-dependent child'' provided by Public Law 99-272 inferred a more restrictive definition, ''...the term ''technology-dependent child'' means a child who has a chronic illness which makes the child dependent upon the continuing use of medical care technology (such as a ventilator).''

In order to more precisely define the term ''technology-dependent,'' the Task Force reviewed over 16 definitions, developed by members. The Task Force also closely reviewed the definition developed by the Congress of the United States, and the Office of Technology Assessment (OTA) in its May, 1987 report.

OTA defined a technology-dependent child as one that:

1. Requires a particular medical device to compensate for the loss of use of a body function; and

2. Requires substantial and complex daily nursing care to avert death or further disability.

OTA further specified four separate populations that might be considered technology-dependent using this definition. These populations are children who:

1. Are dependent on a ventilator at least part of each day; or

2. Require prolonged intravenous nutrition or drug therapy; or

3. Have a daily dependence on other device-based respiratory or nutritional support, including tracheostomy tube care, suctioning, oxygen support or tube feeding; or

4. Children who have other long-term requirements for extraordinary levels of nursing or monitoring in conjunction with a medical device.

This last category might include infants requiring apnea monitors, and often resuscitation, as a consequence of sleep disorders; children with diabetes, chronic kidney failure, hemophilia or other chronic diseases; and children with multiple medical problems who require intense monitoring and medical care as a result of required drugs, devices and therapy.

The two common elements in all definitions were the requirements for a medical device to sustain life, and skilled nursing care on a routine daily basis. One definition substituted ''skilled care'' for ''skilled nursing care'' to provide more flexibility in delivery of services. And, of those definitions reviewed that required an age of eligibility:

- one set ''an age limit,''
- one set the limit at children below age 18, and
- four included children below age 21.

Following review, Task Force members agreed that a technology-dependent child should be one dependent on a medical device to sustain life. They also agreed that although skilled care is most often necessary for these children, skilled care does not imply care delivered by a registered nurse. The use of appropriately trained non-professional staff increases the availability of service personnel, and may be more cost-efficient. After careful consideration of each of the reviewed definitions, the Task Force agreed upon the following working definition:

A technology-dependent child:

- Is a person from birth through 21 years of age (a person who has not reached their 22nd birthday);
- Has a chronic disability;
- Requires the routine use of a specific medical device to compensate for the loss of a life sustaining body function; and
- Requires daily, ongoing care or monitoring by trained personnel.

Case management

Under the Home and Community Based waivers of Title XIX of the Social Security Act, States have been permitted to interpret and define ''case management.'' As a result, there is considerable State-to-State variation.

The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)(P.L. 99-272), Section 9508 provided States with the option to cover targeted case management services under Medicaid without the need to obtain a waiver. In this provision, case management services are defined as ''services which will assist Medicaid-eligible individuals in gaining access to needed medical, social, educational and other services.'' This statutory language again gives States the flexibility to provide their own interpretation of case management.

Although ''case management'' is provided in numerous circumstances, there is no universally recognized definition.

Case management, as defined by the Task Force:

- Is a process which promotes the effective, and efficient organization and utilization of medical, social, educational and other resources to achieve or maintain the maximum potential of the child in the most appropriate and least restrictive environment.
- Is a process of service coordination that is community-based, family centered, and identifies a single service coordinator (case-manager) for each technology-dependent child and family.
- Involves active advocacy on behalf of the child and is characterized by active communication among providers, payers, the child, family and community.
- Ensures a multidisciplinary planning process that includes the family and is reviewed regularly and on an ''as needed'' basis.
- Includes quality care assurances and appropriate monitoring and evaluation mechanisms.

The Task Force also discussed the necessary qualifications of a designated case manager. As no specific background or agency affiliation is necessary, individuals from a variety of disciplines should be encouraged to perform this service. The case manager may change over time depending on location and condition of the child. They also believe that, where possible, the family should be assisted, with appropriate support, to become its own case manager.

Ideally, a case manager should:

- Assist the family to assume case management responsibilities when they are able to do so.
- Provide current information on availability of funding; State and Federal program sources, availability and limits of private health insurance;
- Participate in the development of a discharge plan and transfer/follow-up to next appropriate level of care;
- With the family, coordinate community-based medical, psychological, social and educational evaluation and planning services;
- Facilitate care coordination in accordance with the individualized care plan;
- Monitor and evaluate all phases of the individualized care plan;
- Be a prudent purchaser of multiple services and devices;
- Provide for a consistent quality assurance review of those services delivered to the child and family; and
- Assure continuity of care.

Appropriate Care

In defining ''appropriate care,'' Task Force members first developed their own definitions as a base for discussion. Among components discussed were requirements that home care:

- Not attempt to duplicate an institutional setting;
- Be less costly, in the short term, than institutional care;
- Be planned by a formal managed care program to meet specific needs of individual children;
- Include a separate quality of care system to ensure the program works effectively;
- Include support services necessary to enable care-givers to provide continuous, consistent and competent care, e.g., social services, respite care,etc;
- Include services and equipment necessary to sustain life in the home or community setting;

Also discussed were family services which might include affordable health insurance, transportation, respite care, housing adaptation, parent to parent support, parent training, etc.

The Task Force defines Appropriate care as:

- The type and amount of specialized care required by technology-dependent children to:
    1. Maintain life support, and
    2. Provide an environment conducive to growth and development.
- Appropriate care is documented and managed through the use of an individualized care plan developed and monitored by an interdisciplinary team which includes parents or guardians.
- Appropriate care must include:
    1. Access to needed services, including alternative placement,
    2. Case Management (as defined by the Task Force),
    3. Respite Care,
    4. Developmental/Educational Services, and
    5. Psychosocial services.

To assure provision of appropriate care, families should be supported in their role as caregiver through development of family support groups, networking and information resource centers.

APPENDIX B
LEGISLATIVE HISTORY

The goal of coordinated care for technology-dependent children is the effective organization and use of multiple services and resources to achieve the maximum potential of the child in the most appropriate, least restrictive environment. In assessing how far the ''state of the art'' has evolved toward this goal in the late-eighties, it is noteworthy that the goal itself is the result of the mingling of a number of fundamental trends that have shaped national policy since the 1960's.

Foremost among these trends is the advance of medical technology. The subspecialties of neonatology and critical care pediatrics have evolved, making it increasingly possible to administer sophisticated treatments outside the hospital environment. Numerous restorative, rehabilitative, and palliative procedures have become available in the home setting.

Advocates for the disabled have long stressed the need for comprehensive community-based care and the deinstitutionalization of individuals in mental hospitals and institutions for the mentally retarded. This led to the movement of residents from state hospitals for the mentally ill and efforts to provide care for the mentally retarded and developmentally disabled in the least restrictive environment for their best development and care. This ideal is firmly embedded in P.L. 94-142, The Education of All Handicapped Children Act of 1975; P.L. 93-112, the Rehabilitation Act of 1973; and developmental disabilities P.L. 100-146, the Developmental Disabilities Act, last revised in 1987. These laws have helped to support a continuing emphasis on improved services and enhanced interagency cooperation. They have also provided protection and advocacy services to the developmentally disabled. The extension of the concept of least restrictive environment to children dependent on technology requires a commitment on the part of all providers and payers to seek continually to integrate these children, wherever appropriate, into the mainstream of their communities.

By the late 1970's, spiraling health care costs — particularly nursing home costs — had begun to alarm the Congress and administrators of Medicaid, the federal-state health care financing program for the needy that pays nearly half the nation's long term care bill (Title XIX of the Social Security Act). Inspired by the belief that home and community could reduce Medicaid long term care expenditures if appropriately substituted for institutional care, Congress enacted the Section 2176 Medicaid Home and Community Based Waiver Program as part of P.L. 97-35, the Omnibus Budget Recociliation Act of 1981 (OBRA). In doing so, it recognized the significant role of case management and nonmedical support services — such as personal care, homemaker, day care, respite care, transportation, and minor home modifications — in the sucess of efforts to provide high quality health care in an environment less restrictive than a nursing home.

Enactment of the waiver program closely followed national publicity in 1981, centered by President Reagan on the plight of a technology-dependent child. Katie Beckett is a resident of Iowa. Complications from viral encephalitis as an infant had left her ventalator-dependent. Although 3 1/2-year old Katie's condition was determined stable and her parents wished to care for her at home, she could not be brought home from the hospital without losing eligibility for the Medicaid funding that paid for her costly care. This was so even though costs paid by Medicaid for Katie's care in the hospital — about $12,000 per month — were approximately $10,000 higher per month than the estimated cost of care at home.

Medicaid funding for Katie continued only so long as she remained hospitalized because Supplemental Security Income (SSI) program regulations, which generally determine eligibility of the elderly and disabled for Medicaid, applied to her situation. By statute, the income and resources of parents living in the same household as their child are ''deemed'' available to the child. Medicaid coverage becomes available to a hospitalized child only after thirty days of institutionalization. The child is then considered not to be living in the family household. The parents' income and resources are no longer considered in determining the child's financial eligibility for SSI and Medicaid.

The ''Katie Beckett'' case illustrated the institutional bias in Social Security Act-related health care programs and highlighted the need for greater flexibility in meeting the needs of technology-dependent children from middle income families. The immediate outcome of Presidential attention was establishment of an intra-Departmental board by the Secretary of Health and Human Services (HHS). Active through 1984, the board considered individual ''Katie Beckett'' waiver requests, waiving the SSI deeming requirements in 180 cases. This allowed children in situations similar to Katie Beckett's to receive care at home with Medicaid funding. The long term implication was heightened awareness, both in Congress and in the Administration, of the special medical, rehabilatative, educational, and social needs of these children and the cost associated with the provision of appropriate care.

Since 1981, the Congress and the Administration have continued to identify and foster removal of some organizational and financial barriers that impede access to suitable in-home services for groups at high risk for costly institutionalization.

Third-party payers — private and public — have been encouraged to re-examine their traditional policies favoring istitutional care, modify artificial restrictions on eligibility, broaden coverage of cost-effective community-based health services, and create mechanisms to manage care more effectively. Changes in the SSI ''deeming'' rules to equalize treatment of family income and eliminate institutional bias for all SSI-eligible groups have been proposed, but not enacted. Instead, policymakers have targeted the Medicaid program as the preferred vehicle for most legislation in the 1980's supporting expanded community-based care opportunities for specific high-risk groups. This program, designed for the indigent already receiving public assistance, serves as the payer of last resort for many non-poor technology-dependent children and other high-risk individuals when other sources of payment have been exhausted.

The Medicaid Home and Community-Based Services Waiver Program (Section 2176 of the ''Omnibus Budget Reconciliation Act of 1981 (OBRA),'' P.L. 97-35), was the first of a series of legislative initiatives in the 1980's. These initiatives were aimed at broadening opportunities for the long term care of high-risk groups — including the aged, physically disabled, developmentally disabled/mentally retarded, and mentally ill — through community-based services.

Section 2176 of OBRA, permitted states, the option to expand eligibility and extend coverage for services beyond those normally covered by Medicaid. This allowed care in the community for groups who would otherwise require care in a long term care facility at greater expense to Medicaid.

Subsequent legislation, P.L. 99-272, the ''Consolidated Omnibus Budget Reconciliation Act of 1985'' (COBRA), enacted in 1986, explicitly extended waiver coverage to individuals requiring an acute hospital level of care.

''Model Waivers,'' developed by the Health Care Financing Administration (HCFA) in late 1982, using the statutory authority of Section 2176, have been used by some states to provide services to technology-dependent children. These waivers provide funding for home and community-based services to groups of no more than 50 blind or disabled individuals who — because of SSI family income rules — are eligible for Medicaid only if institutionalized. Model waivers replaced case-by-case review and approval of individual SSI deeming waivers by HHS's intra-Departmental board. The process for approving individual deeming waivers was created early in 1982 by the Secretary of the Department of Health and Human Services as a temporary strategy while states pursued their new waiver options. Individual ''Katie Beckett'' waivers were phased out after 1984.

Despite state difficulty with some waiver limits — particularly the requirement that home and community -based care replace institutional long-term care in a way that is budget-neutral to Medicaid — the Section 2176 waiver program has been a popular option for the states. It allows them greater flexibility in developing long term care systems that incorporate community and institutional components. The waiver program, however, is not a mandatory service under Medicaid. It is simply one option for states in an already fragmented financing system for providing home and community based services. As of December 1, 1987, a total of 116 Section 2176 waiver programs from 46 states were active. Of 88 regular waiver programs in 45 states, approximately half are designed to serve various categories of aged and physically disabled individuals. Four of the regular Section 2176 waiver programs include physically disabled children. These waiver programs are currently serving a total of 285 children with severe physical impairments.

Some of the states whose waivers do not serve chronically ill children have implemented other options to meet their needs. Fourteen states provide community-based care to about 130 children under individual ''Katie Beckett'' waivers granted prior to 1985. Thirteen states have instituted a total of 14 model waiver programs, serving up to 50 disabled children at a time. Another nine states have amended Medicaid state plans under separate legislation making it possible to serve technology-dependent children under Medicaid without waivers.

Succeeding budget reconciliation bills passed since 1985 have progressively expanded Medicaid coverage for uninsured low-income, pregnant women and children. The most recent expansion, enacted in OBRA of 1987, allows states to extend Medicaid coverage to pregnant women and infants with family incomes up to 185 percent of the federal poverty level. Family level can be charged a monthly premium. This premium may not exceed 10 percent of the amount of their gross income,

* FOOTNOTE: *The Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203) has increased the number of individuals who can be served under a model waiver to at least 200. Model waivers are currently serving about 385 children. Section 134 of P.L. 97-248, the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), allows states to amend their Medicaid state plans to provide regular Medicaid services (but not non-medical support services) to all disabled children under 19 living at home, who, because of SSI deeming rules, would be Medicaid-eligible only if institutionalized. An estimated 335 children are currently served under Section 134 state plan amendments.

less child care expenses. OBRA of 1987 also allows states to accelerate coverage of children up to age 5 in families with incomes up to 100 percent of the poverty level. In addition, this legislation extends mandatory Medicaid coverage to children in families meeting AFDC income and resource limits through age 6 and optional coverage of these children up through age 8. Previously (under OBRA of 1986), states could extend Medicaid to pregnant women and infants up to age one with family incomes of up to 100 percent of the poverty level, with phased-in eligibility for children under 5. The age limit for coverage of AFDC-related children had been age five.

Congress has also taken steps within the reconciliation process to improve Medicaid coverage without waivers for groups at high risk of institutionalization. A number of measures have substantially improved options for states to expand their capacity to serve technology-dependent children under Medicaid without waivers. A provision of COBRA of 1985 allows states to target case management services to sub-groups of the Medicaid population without adherence to Medicaid's requirements for statewideness and comparability. The legislation describes case management as ''services that will assist individuals eligible under the state plan in gaining access to needed medical, social, educational, and other services.'' Prior to COBRA's enactment, case management services could be financed by Medicaid only under home and community-based waivers.

In a reconciliation measure to increase the efficiency of community-based care, OBRA of 1986 authorized new funds under the Maternal and Child Health Services block grant (Title V of the Social Security Act) to promote development of community-based services networks and case management for all children with special health care needs. The definition of case management in this provision is similar to that set forth in COBRA amendment to the Medicaid program. A COBRA amendment to the Medicaid waiver authority was intended to encourage cooperative arrangements between the state Medicaid agency and the state Title V agency. In some states, such interagency cooperation is already credited with improving access to coordinated services for children eligible for both programs.

OBRA of 1986 permits states to fund in-home respiratory care services under Medicaid for eligible ventilator-dependent children and adults. Coupled with case management, adoption of this coverage option would make it possible for all states to serve Medicaid-eligible ventilator-dependent children at home without waivers. However, by October 15, 1987, no state had implemented this service option for ventilator-dependent children.

Provisions enacted in COBRA of 1985, aimed at reducing pressure on federal and state Medicaid budgets by increasing obligations of private insurers, could help families of technology-dependent children. The need to maintain continuous health insurance coverage for a technology-dependent child effectively bars some parents from changing jobs. Title X of COBRA of 1985 requires employers to continue group health insurance coverage at reasonable rates for certain employees and their dependents for eighteen months following termination of employment. Employers failing to provide continuation policies will lose federal tax benefits for their contributions to employee group health insurance plans. However, a House-passed provision to further extend the obligations of large self-funded employer health plans was dropped during conference. This provision would have allowed states to tax large self-funded health plans for failure to participate in state insurance risk pools. The continued exemption under the Employee Retirement Income Security Act (ERISA), of employer-based self-funded health plans from participation in state-mandated pools, is generally recognized a a serious barrier to wider adoption of risk pools by states.

One significant Medicaid administrative mandate included in COBRA of 1985 strengthened the authority of state Medicaid agencies to ascertain the legal liability of third-parties to pay for care available under their state plans. A number of actions were specified for states and service providers to ensure that providers do not refuse services to recipients because of potential third-party liability; that states will aggressively pursue third-party claims; and that Medicaid will continue to remain the payer of last resort even in cases where the state agency must pay prospectively such as the Early Periodic Screening, Diagnosis, and Treatment program.

In addition to their health service needs, technology-dependent children have special educational needs. The 1975 Education for all Handicapped Children Act (P.L. 94-142) requires public schools to offer or assure an appropriate education for all children with handicaps and provide services related to that education. Of particular interest to families of infants and toddlers is P.L.99-457, the Education of the Handicapped Act Amendments of 1986. This extension of P.L. 94-142 mandates provision of ''early intervention services'' through the public schools, at little or no charge, to ''developmentally delayed'' or at-risk infants and toddlers aged 0 to 2 and their families. P.L. 99-457 requires that the service needs of each handicapped child be assessed and a written individualized ''family service plan'' developed to meet the identified needs. Similarly to P.L. 94-142, this law could provide funding for community-based services that are not generally covered by private health insurance plans.

P.L. 99-457 emphasizes early intervention and interdisciplinary planning for family-centered, coordinated, community-based integrated health and education services. State implementation of this law is in the early stages. To assure that children have access to public educational programs appropriate to their needs, states are required to establish interagency committees which will include both their Departments of Health and Education.

Other recent Congressional actions have contributed to elimination of some financial barriers to home care for technology-dependent children of military personnel. Military families have faced special challenges in obtaining nonhospital long term care services for these children within the military health care system. This is because Department of Defense policy on ''custodial care, which applies both to the Civilian Health and Medical Program of the Uniform Services (CHAMPUS) as well as to military hospitals, precludes coverage of most services and supplies associated with long term care of technology-dependent children. (See Appendix C.)

A provision in the Defense Authorization Act for fiscal years 1988 and 1989 (H.R. 100-180), authorizes funding for catastrophic protection under CHAMPUS. It provides that dependents of active duty personnel not be required to pay a total of more than $1,000 out-of-pocket for health care received under CHAMPUS' Basic Program during any fiscal year. This provision applies to benefits under CHAMPUS' Basic Program, but not to its special Program for the Handicapped for active duty personnel, which, by law, limits benefits to a maximum of $1,000 per month.

CHAMPUS home care demonstration (HHC) project, which has been providing cost-effective home health and related support services to dependents of active military personnel who would otherwise be receiving hospital care, has recently been expanded and extended for at least two additional years. The expanded project will provide comprehensive case management for patients with exceptionally serious or catastrophic illness.

APPENDIX C

SOURCES OF FINANCING

Introduction

This appendix reviews the major sources of financing for technology-dependent children and their adequacy for funding community-based care. It was prepared for the Task Force on Technology-Dependent Children to aid the Task Force in analyzing financial barriers to home and community-based care. Much of the information is adapted from a Technical Memorandum prepared by the Office of Technology Assessment (OTA) entitled, Technology-Dependent Children: Hospital v. Home Care, May 1987. Some sections have been edited and updated to reflect more recent information.*

*The Task Force gratefully acknowledges the assistance of OTA staff in the preparation of this document. Any interpretations and conclusions, unless otherwise noted, should not be attributed to OTA.

Private Insurance

Children have access to private health insurance through two means: (1) as a dependent of an employee, covered under an employer-based group health policy, or (2) through an individual family policy. According to OTA, only about six percent of all privately insured children fall into the second category.

In 1986, 62 percent of children between birth and twelve years were covered by private insurance as their only source of third-party coverage. There is a direct correlation between family income and mother's marital status and the likelihood of coverage by private health insurance. For example:

- o 86 percent of children with family income above 200 percent of the federal poverty level are covered under private insurance.
- o Only 14 percent of children with family income below 200 percent of the federal poverty level are covered under private insurance.
- o 84 percent of families headed by divorced or separated mothers with incomes between 100 and 200 percent of poverty have no health insurance. 30 percent of children with married mothers in this same income class have no health insurance.
- o 19 percent of all children under 13 — 8.5 million children — had no health insurance of any kind in 1986.

Children with major health problems are less likely to have private health insurance. Approximately 46 percent of noninstitutionalized children with severe limitations of activity have no private insurance, compared to about 26 percent of children without limitations of activity. Reasons suggested by OTA for these disparities include: (1) unavailability of individual coverage for severe disabled children, (2) lack of coverage of preexisting conditions under group plans, (3) lack of coverage beyond lifetime maximum limits, and (4) parental decisions to rely on public sources of support.

Adequacy of Coverage

Adequate financial resources are not assured simply because a child is covered under a private health insurance plan. Exposure of the insured to out-of-pocket expense varies according to the insurance plan. It depends upon the following variable features:

- First dollar deductible—the amount the insured pays before becoming eligible for coverage.
- Coinsurance rate—the percentage of costs paid by the insured.
- Catastrophic stop-loss on out-of-pocket expenses—an annual upper limit on a beneficiary's out-of-pocket payments for services.
- Overall plan maximums—limits on the total amount the insurer will pay out on the policy.
- Limits on covered services—limits on the amount, duration, or scope of services covered.

Because their care is complex and expenses are typically catastrophic in nature, the most important features of private health benefit plans for technology-dependent children are the overall plan maximums, catastrophic stop-loss provisions, and the covered services.

Although there appears to be an overall trend toward higher overall maximum limits, some reaching $1-million or more, it is probable that over one-half of privately insured families have insurance that is inadequate for the catastrophic expenses associated with long-term care of technology-dependent children. The impact of low lifetime maximums is demonstrated with preliminary data from the Maryland and Illinois home care programs for children requiring ventilator support.

- Maryland children if hospitalized would on average exceed a $250,000 maximum in about a year, even if the insurer paid only 80 percent of the charges. The average length of hospital stay for these children was 14 months.
- At home, the lifetime maximum would be exceeded within three years.
- In Illinois, 42 of the 63 children in the program were supported exclusively through Medicaid, twenty-three because their private insurance had lapsed.

The situation is somewhat better with respect to catastrophic stop-loss insurance, which can prevent young families from being financially impoverished by heavy coinsurance requirements in the early months or years of expenditures for a technology-dependent child. In 1984, more than three-quarters of private insurance plans had an annual catastrophic limit on out-of-pocket expenses. However, catastrophic stop-loss coverage does not lessen a family's exposure to lifetime maximum benefit limits.

Home care coverage is an especially important service for technology-dependent children, but is frequently not covered or not structured to meet the needs of these children. For example:

- Almost one-half of employees in medium and large businesses were without home health benefits in 1984. Emphasis on cost containment has lately resulted in an increase in the number of insurance plans adding home health care benefits. While 11 percent of plans in a recent survey of large firms added home health benefits between 1980 and 1982, OTA reported that most children would not be eligible under their current plans, including HMO's, because of limited home health benefits.

- The structure of home health benefits typically does not allow for the special needs of a technology-dependent child who requires continual nursing care. For example, over 90 percent of Blue Cross/Blue Shield plans covered home health services in 1984, 95 percent of them limited the number of professional nursing visits.

- Standard policies tend to mirror the stringent requirements of the Medicare home health benefit. Most cover only intermittent skilled nursing services immediately following an acute care hospital stay. Respiratory therapy is not a covered service in almost 25 percent of the surveyed Blue Cross/Blue Shield plans. None included hourly nursing as a regular service. Private health insurers generally follow the same approach as Blue Cross plans.

Thirteen states have used regulatory authority to require health insurers to offer home health benefits. OTA views state action to mandate home health benefits in health insurance plans as unlikely to be an effective means to increase home health coverage for technology-dependent children. This stems from the increase tendency of employers to provide health benefits to employees on a self-insured basis. Self-insured plans are exempted from state regulations by Section 514 of P.L. 97-473 (ERISA). Further increases in mandated benefits by states are likely to increase the number of employers choosing to self-insure.

Recent Initiatives

Several insurance companies have initiated individual benefits management programs, under which they pay for otherwise uncovered services in the home as long as doing so reduces benefit payments. Contractual limits are typically waived only for certain high-cost patients whose cases are considered on a case-by-case basis. While a recent survey showed that 53 percent of employers had an individual benefits management program, they do not all operate to encourage nonhospital care of technology-dependent children. Individual benefits management plans do not eliminate the problem of low overall limits. They can extend the length of time before an overall plan maximum limit is reached, but do not eliminate the ceiling on total payments by the insurer.

A small number of private insurance plans have considered increasing coverage of specific complex home services to groups of beneficiaries. Most common are pilot home care programs for chronically ill children and adults, including a few specifically for children dependent on ventilator or intravenous nutrition technologies.

Medicaid

The Medicaid program is in reality 54 separate state-administered programs jointly funded by state and federal governments. It provides health services to very poor people who are also aged, blind, disabled, members of families with dependent children, or first-time pregnant women. In 30 states and the District of Columbia, persons in these categories can also qualify for Medicaid as ''medically needy'' if their medical expenses are high enough to effectively render them poor. Medicaid is normally the payer of last resort.

Eligibility

- All persons receiving payments under the Aid to Families with Dependent Children (AFDC) program are automatically Medicaid-eligible.

- All aged, blind, and disabled individuals (including children) who receive cash payments under the Supplementary Security Income (SSI) program in most states are eligible. (States may limit Medicaid eligibility to individuals who meet requirements more restrictive than those under SSI.) The linkage of Medicaid eligibility to SSI payments and payment rules is central to issues involving home care for technology-dependent children. To be eligible for SSI, an individual must be disabled and have income and resourses no higher than established state limits.

- By statute, the income and resources of certain relatives living in the same household as the individual — specifically parents and spouses — are assumed or ''deemed'' available to the individual. Following one month of institutionalization the individual is considered not to be living in the family household and the relative's income and resources no longer are considered in determining eligibility.

- The SSI-Medicaid relationship allows a child with long-term complex problems and inadequate private health insurance to receive hospital and other institutional services under Medicaid without regard to the family's income. This linkage has assisted numerous technology-dependent children not otherwise Medicaid-eligible to receive hospital services without impoverishing their families. However, it also encourages institutionalization of persons who could be cared for at home if Medicaid financing were available.

- Until 1981, children receiving expensive care in hospitals or other institutions were unable to receive Medicaid reimbursement for equivalent care at home because once home their families' resources would be deemed available to them. Since then, waivers have provided states with limited Medicaid payment options for less expensive home care.

Coverage and Reimbursement

The degree to which health services are covered under a state's usual Medicaid rules and the way they are paid affect the setting and the amount of care a technology-dependent child receives.

- Medicaid payment may cover only a fraction of total hospital costs of caring for a technology-dependent child. States may pay for hospital care through cost reimbursement with day limits; a prospective payment system; or capitation through prepaid health plans. These methods all provide incentives to hospitals to limit or reduce the time a patient stays. If a child cannot be cared for outside the hospital, the hospital is faced with providing indefinite charity care to that child.

- Medicaid programs are required to cover only certain basic services for Medicaid-eligibles. States may also provide optional services based on state need.

- States are not required to cover either pediatric nursing home care or pediatric home care. However, if they cover nursing home care they must also cover home health services.

- Covering home care also includes providing a set of specified minimum services. Fifty-three states cover pediatric home care under their regular Medicaid programs. They must also provide home nursing visits, medical equipment and supplies.

- States have the option to authorize home respiratory care services and case management. However, Medicaid home health services vary dramatically in amount, duration, and scope even where they are provided.

Medicaid Home Care Financing Options

Few regular state Medicaid programs cover the full range of services needed by a technology-dependent child in a nonhospital setting. Over the past five years, concerns about limitations on Medicaid eligibility and coverage have led to legislative and regulatory changes allowing states the option to cover technology-dependent children and other persons needing long term care.

- Individual ''Katie Beckett'' Waivers were phased out after 1984. These were created in 1982 by the Secretary of Health and Human Services while states pursued options to address the problems of individuals whose deinstitutionalization would result in loss of SSI and Medicaid eligibility. Waivers of the deeming requirements were granted on a case-by-case basis following determination that care provided in the home would be both less costly and of equal quality as institutional care. Once approved, a waiver remains effective until it is no longer appropriate or until the child reaches 19.

  These waivers permitted states to limit expanded Medicaid eligibility to a small number of extraordinary cases. They could be used to aid in deinstitutionalization and to cover disabled children already at home. The chief drawback of individual waivers was that they only entitled individuals to regular Medicaid services already offered by the state. States with few Medicaid home care benefits could not use this option unless additional sources of home care financing were available to the child.

o Regular Home and Community-Based (2176) Waivers. Authorized under Section 2176 of OBRA of 1981 (P.L. 97-35), Medicaid home and community-based Health Care Financing Administration (HCFA) waivers enable states to finance a variety of non-medical support services in the home not usually covered by Medicaid for recipients who would otherwise need more costly institutional care. Waiver applications are submitted to HCFA by states. Once approved, waivers are effective for a three year period and can be renewed for five year periods. There is no limit on the number of waivers which can be granted to a state.

For approval, a state must show that estimated average per capita Medicaid expenditures for all services provided under the waiver to all recipients will not exceed what they would have been without the waiver. Waiver applications to serve technology-dependent children must compare the cost of their home care to the cost of hospitalization using a cost formula prescribed in regulations. They are expected to show that the total cost of home and community-based (HCB) services is not greater than the cost of institutional care and that the waiver will reduce the number of Medicaid recipients receiving institutional care.

Eligibility is limited to Medicaid recipients who, in the absence of HCB services, would require long term care in a hospital, skilled nursing facility, or intermediate care facility for the mentally retarded (ICF/MR). States may restrict eligibility for waiver participation to recipients residing in certain geographic areas in the state; to individuals being deinstitutionalized; or to particular individuals for whom the Medicaid cost of providing HCB services is less than the cost of providing institutional care.

States may expand income eligibility for the target population beyond that of the regular Medicaid program in two ways:(l) by not deeming a certain portion of the family's income to be available to an individual receiving care at home; or (2) by raising the Medicaid income standard to a level equal to three times the maximum payment made to an individual under the SSI program. (Individuals becoming eligible under this higher income standard are required to contribute to the cost of their care.)

States may provide services under the regular waiver that are otherwise not covered by Medicaid, such as homemaker/home health aide, respite care, minor home modifications, and habilitation, as well as augmented regular Medicaid services, such as hourly shift nursing, personal care, medical supplies, and durable medical equipment. While these waivers can be used to serve small groups of disabled children who otherwise would have been hospitalized, states generally use them to serve large and more inclusive populations of the elderly and mentally retarded.

States appear reluctant to waive the SSI deeming rules for large numbers of recipients under regular waivers. Many states seem to prefer to control the number of very high-cost individuals coming into the program through use of ''model'' waivers.

o Model Home and Community-Based Waivers. HCFA developed a ''model'' HCB waiver in December 1982 to encourage states to provide HCB services to limited groups of blind and disabled individuals who would otherwise be ineligible for Medicaid outside of an institution. The model waiver was intended to replace the individual board-approved ''Katie Beckett'' waivers. A streamlined application was developed to assist states to move quickly through regular waiver application process.

A model waiver differs from a regular waiver in two essential respects: (1) It was designed to serve no more than 50 blind or disabled children and adults at any one time (2) It may provide a waiver of the SSI deeming rules to permit Medicaid eligibility for noninstitutional services.

States applying for model waivers must meet all basic requirements for regular HCB waivers, but are only required to offer a single waivered service, such as case management. As under regular waivers, services may be targeted to particular subgroups of the disabled population. States can admit into a model waiver program only those individuals whose home care costs do not exceed their estimated institutional costs. Under a regular waiver states need only show that Medicaid's average per capita costs with the waiver would not exceed what they would have been without the waiver.

Model waivers have certain advantages for states interested in serving children who would otherwise be hospitalized. (1) They provide a cap on costs and an opportunity to gain experience with home care on a small scale. (2) The standardized application permits isolation of a small, closely-defined target group for whom program savings under home care can be dramatically documented on a case-be-case basis thus speeding approval.

The chief disadvantage of model waivers until recently has been their 50-person limit. Some states, particularly large ones, were required to apply for more than one waiver to serve their populations adequately. OBRA of 1987 has increased the number of individuals who can be served under a model waiver to at least 200.

o State Plan Amendment. Under a provision enacted in TEFRA of 1982 (P.L. 97-248), states may amend their state plans to provide regular Medicaid coverage to children under age 19 living at home who, because of SSI deeming rules, would be Medicaid-eligible only if institutionalized. States must ascertain for each child that home care is appropriate, and that the cost of this care does not exceed the cost for institutional care. Under a plan amendment, all children in the state meeting the eligibility criteria, whether or not institutionalized, must be permitted to participate.

The chief advantage of this option is that no waiver is required. States are free to develop their own implementing rules and to discontinue coverage for this group of children at any time. This option has not been especially popular with states, families, or providers. Provision of regular Medicaid coverage in a state offering only limited home health care services may not meet the needs of a technology-dependent child.

o In the 23 Medicaid jurisdictions without either waivers or a state plan amendment, technology-dependent children have the same Medicaid home care coverage possibilities that they did prior to availability of these options. Children who qualify for Medicaid as categorically or medically needy can receive regular Medicaid home health services authorized under the state plan. In a few states, the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, may cover some additional home services. EPSDT is a mandatory service under Medicaid which must be offered to all Medicaid-eligible children. EPSDT's function is to detect and treat correctable abnormalities, such as a vision and dental problems. Under EPSDT, states may, if they wish, offer services to poor children without making them available to other Medicaid recipients.

Factors Limiting Use of Medicaid Options

Although a number of states have chosen to provide home care to technology-dependent children under available options, many of these children are still not receiving the benefit.

Section 2176 of the HCB waiver programs — particularly regular waivers — were designed to serve populations other than physically impaired children. Thus, the usefulness of these programs for technology-dependent children is limited.

Qualifying for coverage under a waiver depends on how each individual waiver is structured by the state with regard to income eligibility, target group eligivility, service coverage, and cost-saving considerations.

Specific ways in which states can limit access include: (1) Not waiving deeming rules under a regular waiver. (2) Restricting eligibility for a model waiver only to certain disease categories. (3) Limiting waiver coverage only to children actually discharged from an institution. (4) Limiting reimbursable Medicaid hospital days making cost savings to Medicaid from home care difficult to demonstrate. (5) Not expanding or otherwise augmenting regular Medicaid home care services when using individual waivers or a state plan amendment in ways that meet the needs of technology-dependent children.

A state's ''attitude'' toward financing home care for high-cost children is a major determinant of how many technology-dependent children receive waiver coverage. A survey conducted by the Task Force showed that states do not widely publicize the availability and requirements of their programs. This leads to confusion and misinformation on the part of parents, providers, and even among State Medicaid agency staff.

Many waiver amendment programs have experienced long initial delays, often owing to state inexperience or to a shortage of case managers and home health personnel. Where this has happened, disabled children, like other program eligibles, have not been able to receive home care services.

State Medicaid Activity under Available Options

Most states choosing to provide extended Medicaid home care services to technology-dependent children have chosen to serve them under waivers for the physically disabled. A few states serve these children using a waiver for the mentally retarded/developmentally disabled.

As of November 1, 1987, 32 states and territories were serving about 1,135 technology-dependent and other physically disabled children through a waiver. Four States (CA, KY, MO, and MT) used regular HCB waivers to serve approximately 285 children. Thirteen states (CT, GA, IA, IL, KY, MD, MN, NJ, NM, NC, OH, PA, and SC) provided services to about 385 children through 14 separate model waivers. Nine states (AK, GA, ID, MA, ME, NV, RI, SD, WI) and the Northern Mariana Islands have adopted Section 134 (TEFRA) state plan amendments, serving an estimated 335 children. Another 14 states (CO, DE, GA, ID, IL, IN, LA, MA, NV, NJ, NM, NY, OR, and WA) received approximately 130 individual ''Katie Beckett'' waivers before these waivers were phased out.

Technology-dependent children account for over 60 percent of the waivered home care cases. Among other waivered physically disabled children, about 25 percent have central nervous system disorders such as cerebral palsy, multiple sclerosis, quadriplegia, spina bifida. Another 10 to 15 percent have congenital metabolic or immune disorders including cystic fibrosis, congenital heart disease, multiple congenital anomalies or accidental injuries.

Recent initiatives

Over the past several years, Congress has taken action within the budget reconciliation process to add coverage for a variety of benefits and eligibility groups under Medicaid and other indigent care programs. Budget reconciliation measures enacted since 1985 have progressively expanded maternity and child care under Medicaid for low-income families and substantially improved opportunities for states, if they choose, to serve technology-dependent children and other groups at risk for institutionalization under Medicaid without reliance on waivers.

COBRA of 1985 (P.L. 99-272) allows states to offer case management services to targeted populations without having to meet Medicaid's statewideness and comparability provisions. Prior to COBRA's enactment, case management services were normally offered only under HCB waivers, even though they could be built into a state's EPSDT program.

OBRA of 1986 (P.L. 99-509) permits states to cover at-home respiratory care services to ventilator-dependent children and adults without obtaining a waiver. Coupled with case management, this coverage option could enable all states to serve ventilator-dependent children at home. Some states already have been providing home-based respiratory care as part of their regular home health benefit, usually with preauthorization. The provision covers services provided on a part-time basis by a respiratory therapist or other person skilled in respiratory therapy.

To be eligible for home-based respiratory care, an individual must: (1) Be dependent on a ventilator at least six hours per day. (2) Have been a ventilator-dependent inpatient for 30 consecutive days, or the maximum number of days authorized under the Medicaid state plan, whichever is less. (3) Have adequate social support services to be cared for at home. (4) Wish to be cared for at home. (5) Require inpatient respiratory care for which Medicaid would pay if home-based respiratory care services were not available. The home respiratory care option became effective upon enactment of OBRA of 1986. As of November 1987, no state had implemented this service option.

OBRA of 1986 permits states to expand financial eligibility of pregnant women and children for Medicaid. Beginning April 1, 1987, states were given the option to extend Medicaid eligibility up to 100 percent of the federal poverty level on a phase-in basis to children up to the age of five.

OBRA of 1987 (P.L. 100-203) accelerated coverage of children up to age five in families with incomes up to 100 percent of the federal poverty level. States may now opt to extend Medicaid eligibility to children born after September 30, 1983, without a phase-in. This legislation also extended mandatory Medicaid coverage to children in AFDC families up to age six, for children born on or after September 30, 1983. Optionally, states may extend coverage to AFDC children up to age eight.

OBRA of 1987 further extended Medicaid benefits for pregnant women and their families. It allows states to extend coverage to pregnant women and infants with family incomes up to 185 percent of the federal poverty level. Families above 150 percent of the poverty level can, at state option, be charged a monthly premium. This premium may not exceed 10 percent of the amount of their gross income, less child care expenses.

The value of these new Medicaid options could be substantial, particularly the new opportunity for low-income families to ''buy-in'' to Medicaid coverage. They could benefit an unknown number of technology-dependent children in low-income families whose incomes are still too high to meet state-set AFDC payment standards that would qualify them for Medicaid as categorically needy.*

Given the enormous health care expenses incurred by all families of technology-dependent children, however, the usefulness of these new Medicaid options remains limited. Middle-income families, as well as poor families, face enormous medical expenses associated with their children's care. In states with medically needy programs, these families may become eligible by deducting or ''spending down'' their Medicaid-covered expenses. Since these expenses are often greater than a family's take-home pay, middle class families with nondisposable resources have few alternatives under Medicaid to continued institutional care.

Title V Services for Children with Special Health Needs

The program for Children with Special Health Needs (CSHN), until recently called Crippled Children's Services, was enacted under Title V of the Social Security Act of 1935. It was the only major public source of support for the care of low-income chronically ill children until the mid-1960's when Medicaid and a variety of other categorical health care programs began. The program has undergone major changes over the years. The original legislation provided federal matching funds for a number of state-provided services, including maternal and child health services, crippled children's services, SSI for disabled children, hemophilia treatment centers, and other grant programs aimed at specific groups or health problems.

The Omnibus Reconciliation Act of 1981 (P.L. 97-35) replaced these categorical grants with a single Maternal and Child Health block grant to each state, eliminating most federal requirements for specific services and allowing greater state discretion. Special funding was continued for Special Projects of Regional and National Significance (SPRANS), training, and genetic disease and hemophilia projects. Programs for children with special health care needs (CSHN) in many states have expanded from providing services to children with crippling conditions, such as polio and cerebral palsy to serving children with a wide range of chronic health conditions including dependence on ventilators.

*Not all poor children are eligible for Medicaid. Financial eligibility is linked to the appropriate state payment standard (AFDC or SSI), which varies considerably from state-to-state. For example, 7 states set AFDC payment standards at or above 75 percent of the federal poverty level; 16 states have payment standards between 50 and 74 percent of the poverty level; 24 states have payment standards between 25 and 49 percent of poverty; and 4 states set their standards below 25 percent of poverty.

Extent of Coverage

In most states, the CSHN program plays a significant role in the care of chronically ill children. Under the MCH block grant, every federal dollar must be matched by three state dollars. In 1983, $67 million in federal funds went to handicapped children's services, or about 23 percent of the total MCH block grant. States spent an additional $247.6 million, some of which were MCH matching funds.

The CSHN program is the only broad-based program in which the organization and financing of care are combined. Services offered by states are diverse and extensive. Most states spend program funds on screening and treatment of handicapping conditions. They also fund a variety of ongoing support services, including case management and counseling. A few operate state-owned hospitals for handicapped children. State CSHN services are typically provided through state health agencies and physicians on a fee-for-service basis.

Federal law prohibits imposing fees on low-income women and children. Where fees are imposed, they must reflect the income, resources, and family size of beneficiaries. Some states have sliding fee schedules.

In most states, CSHN is a strongly clinic-based program, both providing and reimbursing for covered services. CSHN is often coordinated with Medicaid with CSHN providing services and Medicaid reimbursing the clinic for services provided to Medicaid eligibles. Despite its traditional clinic-based emphasis, most CSHN programs fund or provide varying amounts of home care services such as home nursing and respite care as well as case management and training for families of technology-dependent children. Because they offer more flexibility in implementation, some states have chosen their state CSHN programs as the primary vehicle for providing and/or coordinating home services to technology-dependent children.

The role of CSHN as a source of case management and coordination for children served under Medicaid home and community-based waivers has been particularly strong. In 1985, Congress amended the Medicaid waiver authority (Section 9502 of COBRA) to encourage the state Medicaid agency, whenever appropriate, to enter into cooperative arrangements with the state CSHN agency in order to assure improved access to coordinated services for children eligible for both programs.

The CSHN programs have historically been disease-oriented and perceived as more active advocates of care for disabled children than the Medicaid program. Because eligibility, covered services, and payment mechanisms for both Medicaid and CSHN services vary so dramatically, a child might have access to excellent noninstitutional services in one jurisdiction but qualify for little or no assistance in another. A state that offers little Medicaid assistance to a child may offer substantial services through its CSHN program while the reverse might be true in another state.

Recent Initiatives

CSHN programs have been strongly supportive of family-centered, community-based, coordinated services for technology-dependent children. Congress has reinforced this commitment in recent budget reconciliation legislation. OBRA of 1986 authorized additional funds under the Maternal and Child

Health Services block grant to promote development of community-based services networks and case management for all children with special health care needs. The definition of case management is similar to the case management provision enacted in COBRA of 1985 as a Medicaid option.

During the 1987 reconciliation process, House and Senate conferees agreed to jointly request the Office of Technology Assessment to conduct a new study on the medical expenses of families of children with special health care needs, eliminating any duplication of subjects already under study.

Beginning in 1983, under Title V demonstration grants for Special Projects of Regional and National Significance, three state CSHN programs — Illinois, Louisiana, and Maryland — have become a significant source of funded care for technology-dependent children. These three state programs were aimed at developing appropriate long term care for ventilator-dependent children, including a regionalized system of care and a comprehensive coordinated care model.

Although the SPRANS programs of the three states have differed in some ways, all emphasize training of parents and professionals, case managed care, and care in nonhospital settings. While focusing attention on ventilator-dependent children in the community, these SPRANS projects and those in certain other states have all centered on the CSHN program as a key coordinator of services.

CHAMPUS

The Department of Defense (DOD) provides access to health care for family members of military personnel through two interdependent systems: (1) Through military treatment facilities — hospitals and clinics — operated by each of the four branches of the Armed Services. (2) Through the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), which supplements and shares the costs of care not available in military treatment facilities.

There are approximately six million CHAMPUS beneficiaries. In 1985, approximately 45,289 CHAMPUS beneficiaries were born. Of these neonates, there were 503 whose cost of care exceeded $50-million dollars — more than $50,000 each. They represent a small number of the technology-dependent children receiving health services through DOD.

Extent of Coverage

Care not available through military treatment facilities may be financed through CHAMPUS in the community in two ways:

- o Regular home health benefits—including durable medical equipment, oxygen, parenteral and enteral nutrition terapies, physical therapy, skilled nursing care, medications and medical supplies, and physician visits.

- o Program for the Handicapped (PFTH) - a special CHAMPUS program for active duty military personnel which provides financial assistance when a member's moderately or severely mentally retarded or seriously physically handicapped dependents are excluded from appropriate public programs or institutions. Benefits authorized under the PFTH include disgnostic services, inpatient, outpatient, and home treatment, rehabilitation, training, special education, institutional care, durable medical equipment and supplies, and certain transportation. Skilled shift (hourly) nursing care, especially important for some technology-dependent children, is also covered.

The PFTH is limited by law to a maximum of $1,000 per month. This sum is inadequate to meet most technology- dependent children's initial equipment and service needs, but generally adequate in combination with other available and appropriate resources to fund subsequent skilled care. Prior approval is required for all PFTH-covered services and supplies.

Adequacy of Coverage

Military families with technology-dependent children face special challenges in obtaining nonhospital long term care services within the military health care system. Like many private health insurance plans, DOD regulations prohibit both military hospitals and CHAMPUS (for both regular and PFTH benefits) from providing, or paying for ''custodial care''. DOD defines ''custodial care'' as care rendered to a patient who:

- has a mental or physical disability that is expected to be prolonged;
- requires a protected, monitored, or controlled environment, whether in an institution or in the home;
- requires assistance to support the essentials of daily living; and is not under active treatment that will reduce the disability to the extent necessary to enable the patient to function outside the protected environment.

As currently interpreted by CHAMPUS and most military hospitals, DOD's policy on ''custodial care'' precludes coverage of most services and supplies associated with long term care of technology-dependent children. This policy is currently being reviewed. A proposed amendment to this rule would permit payment for medically necessary inpatient hospital care required for the custodial condition. Nevertheless, if a military hospital or a CHAMPUS intermediary judges a technology-dependent child ''custodial'', the child is eligible only for limited home care benefits. These include one hour of nursing care per day, prescription medications, and medical supplies.

The CHAMPUS ''custodial'' child's care often must be coordinated with military and civilian health, education, and social services into a multidisciplinary plan and augmented with available community resources for which military families are eligible. Many military families are not eligible for Medicaid. Military families, however, may take advantage of the limited amount of funding through the PFTH, which is not available to the civilian population.

Recent Initiatives

In July, 1986, CHAMPUS began a two-year Home Health Care (HHC) demonstration project for family members of active duty personnel. Persons who would otherwise be receiving hospital care can receive extensive home health services — including skilled shift nursing care — and related community support services which are medically necessary, appropriate, and cost-effective. Children dependent on nutritional or respiratory support or who are receiving intravenous drug therapy are eligible for this program only if they are receiving ''inpatient hospital care that is an otherwise authorized CHAMPUS benefit.'' This limitation still excludes technology-dependent children whom DOD determines ''custodial''.

Between July of 1986, and December 7, 1987, 58 requests for the HHC demonstration were received; 28 of these were approved. Most requests have been for technology-dependent children. The majority of disqualified applicants failed to meet the hospital level-of-care criteria. Alternative home care benefits were offered under the CHAMPUS Basic Program or the PFTH to those disqualified. Parents were assisted in locating resources available to the civilian population. Costs under the HHC demonstration reflect a 27 percent to 45 percent cost savings compared to hospitalization. The cost to initiate the first month of home care is consistently higher than subsequent months. It is estimated that subsequent months of home care will reflect a 30 percent to 50 percent cost savings.

A provision in the Defense Appropriations Act of 1988 continues the HHC demonstration for at least two additional years with a mandate to expand eligibility that will include technology-dependent children. In addition, it expands the HHC on a limited geographic basis to provide comprehensive, individualized case management for patients with ''exceptionally serious, long-range, costly and incapacitating physical or mental conditions''.

Other recently-enacted legislation for the military authorized funding for catastrophic protection under CHAMPUS. It provides that dependents of active duty members not be required to pay a total of more than $1,000 out-of-pocket for health care received under CHAMPUS' Basic Program during any fiscal year. The PFTH was not included in this provision.

Other Public Programs and Services

Nearly all persons who become dependent on technological devices before age 22 would qualify as developmentally disabled under the federal Developmental Disabilities Act which assists states to develop a comprehensive and coordinated array of services for persons with developmental disabilities. Persons are regarded as developmentally disabled if they have a severe chronic condition which: (1) is attributable to a mental or physical impairment, or combination of impairments; (2) is manifested before age 22; (3) is likely to continue indefinitely; and (4) results in substantial functional limitations in at least three areas of life activity.

The Administration on Developmental Disabilities (ADD), located in the Office of Human Development Services in HHS, funds four programs, all of which have implications for technology-dependent children. The Basic State Grant program is used to operate state Planning Councils in every state which implement plans to improve and coordinate services to developmentally disabled persons and to fund projects to stimulate development or improvement of services. ADD also funds University Affiliated Programs, ongoing centers which carry out interdisciplinary training, conduct demonstrations, and provide technical assistance. A third program, Projects of National Significance, carries out research and demonstrations which have national significance.

Use of these programs by technology-dependent children and other developmentally disabled persons is inhibited by limited funding. If fiscal 1988, slightly over $70-million was appropriated for these three programs. Another inhibiting factor is the traditional orientation of the developmental disabilities programs toward persons with mental retardation.

A fourth ADD program may have more potential to affect services provided to children who are technology-dependent. Grants are provided to states to establish Protection and Advocacy Agencies to protect the legal and human rights of developmentally disabled persons. To assure independence, the protection and advocacy function cannot be delegated to any agency which provides treatment, services, or habilitation to persons with developmental disabilities. Protection and advocacy is the only generic service directly funded by ADD.

Protection and Advocacy agencies may provide assistance in obtaining needed services, legal counsel up to and including court action, and other assistance to developmentally disabled persons. In some cases, they mount class action suits. Protection and Advocacy agencies have assisted children who are technologically-dependent to obtain services in the past. It is an area in which there could be growing involvement.

Among other federal or state-financed programs for which technology-dependent children could be eligible are:

- Cash payments, including state supplementary payments in some states, made to noninstitutionalized disabled individuals whose income and resources qualify them for the Supplementary Security Income (SSI) program.

- Federal-State adoption and foster care incentive payments under Title IV-E of the Social Security Act, including provision of Medicaid for handicapped or other children with special needs.

- Certain in-home services available to low-income individuals under federal and state-funded Title XX Social Services block grants. Services may be provided as a means of reducing inappropriate institutional care, and may include homemaker, home health aide, transportation, and other home support services that can supplement Medicaid-reimbursed services.

States may also have their own special programs funded solely through state and local taxes, that provide benefits to targeted groups. In some states these programs represent an important, if small, source of support for chronically ill children. For example, the OTA study describes a Wisconsin State-only program providing "gap-filling" funds to individuals at risk of institutionalization.

Wisconsin also has a family support program, separate from SSI, that provides up to $3,000 per year in cash to families with severely disabled children living at home. Many of these initiatives are state-continued offspring of former Federal categorical child health programs or demonstrations no longer funded under the MCH block grant. Hemophilia Treatment Center projects and Genetic Disease programs are examples.

There is no central source of data on any of these state-based categorical programs, or on the number of children they serve. Some states elect to cover specified groups or individuals for Medicaid services entirely at their own expense. These groups are commonly referred to as ''state-only'' eligibles. Programs for state-only eligibles typically finance indigent or uncompensated care. Each state-only program is unique and relevant program data is not required to be reported to federal Medicaid program authorities.

In 1985, 34 states reported the existence of 41 separate indigent care programs at the state or county level. The number of recipients of medical assistance covered by these programs ranged from 95 in South Dakota to almost 250,000 in New York. Total fiscal year 1983 expenditures were $2.3 billion, ranging from $310,000 in New Mexico to almost $535,000 in New York.

These state and county indigent care expenditures were in addition to the states' share of Medicaid, state expenditures on specific diseases, and direct funds given to hospitals to help offset costs of uncompensated care.

Adequacy of Coverage

The resources available from publicly-funded sources for chronically ill children can be enormously varied depending on where a child lives and on the access that child's family has to appropriate information. Until recently 1986, there was no centralized source for information on state assistance programs for the medically indigent. This lack of information underscored the indispensability of sophisticated and knowledgeable professionals in helping families locate and coordinate sources of financing and available services. Within the past year, state-by-state information on state-only indigent care programs has begun to be compiled regularly by George Washington University's federally-sponsored Intergovernmental Health Policy Project.

Recent Initiatives

In addition to establishing or expanding indigent care programs, states have been considering a number of health care financing strategies that could possibly reduce the problems of underinsurance and uninsurance among children with long term, high cost medical needs. These approaches were outlined in testimony begore the Task Force. Among them are:

- State-mandated high-risk pools, available in Connecticut, Florida, Illinois, Indiana, Iowa, Minnesota, Montana, Nebraska, North Dakota, Tennessee, and Wisconsin;

- State financed catastrophic coverage, available in Alaska, Maine, Minnesota, New York, and Rhode Island; and

- o State-mandated availability of catastrophic coverage, proposed by the National Association of Insurance Commissioners (NAIC) as model state legislation, but as yet not enacted by any state.

The purpose of risk pools is to offer individual health insurance policies to people considered poor risks because of pre-existing conditions. Risk pools help few poor people in obtaining insurance because the premiums are typically high. But they do help to prevent high medical expenses from impoverishing ill middle income people. They offer states a potentially valuable, if limited means to reduce the number of medically indigent people and the amount of uncompensated care.

During 1987 reconciliation deliberations, a House-passed bill that would have allowed states to tax large self-funded health plans for failure to participate in state health insurance risk pools was not adopted. The continued exemption, under the Employee Retirement Income Security Act (ERISA), of employer-based, self-funded health plans from participation in state-mandated pools, is generally recognized as the most serious barrier to wider adoption of risk pools by states.

Charitable Organizations

More than twenty national charitable organizations are active in supporting research and services to aid disabled children. They range in size from large organizations such as the National Easter Seal Society to small groups such as the Retinitis Pigmentosa Foundation. The majority focus on single or closely-associated sets of diseases. These organizations have widely diverse missions, organizational structures, and program emphases.

Extent of Coverage

Charitable organizations are a visible source of research and services for the disabled. Supported by community fund drives and private contributions, the 22 charitable organizations belonging to the National Health Council spent approximately $1.4 billion in total program outlays in fiscal year 1985. Expenditures were for public education, research, community services, professional education, and political advocacy, as well as for indirect or direct provision of patient services.

Charitable organizations spend varying amounts on direct patient services, including medical services and patient education, public and professional education, and community services. 1985 spending for these services ranged from 11 percent of total outlays for the March of Dimes to 93 percent of total outlays for the National Easter Seal Society.

Adequacy of Coverage

Because of relatively small budgets and generally strong research orientations, most major national charitable organizations are not a dependable source of financing for the comprehensive services needed by technology-dependent children. They typically supplement services not otherwise reimbursable, including transportation, educational and recreational activities, therapies, and special medical equipment. Because there is no strong relationship between prevalence of a chronic condition and relative magnitude of foundation support, children with certain disabilities have more resources available to them than others.

Recent Innovations

OTA concludes that extension of private and public health insurance benefits into the home setting may replace charity care, to some extent, as a source of financing for technology-dependent children. Routine reimbursement for care at home would close some of the service gaps now being filled by charitable organizations, including local community and religious organizations. It would also strengthen care coordination and skilled nursing coverage, two areas in which charitable organizations have not been active.

APPENDIX D

GLOSSARY

Acute-care hospital: A hospital in which the average length of stay is less than 30 days.

Apnea monitor: A medical device that detects the cessation of breathing.

Asphyxia: Lack of oxygen resulting in suffocation or near-suffocation.

Augmented care: Care of a greater level, scope, or duration than that normally provided under a particular program or protocol.

Bronchopulmonary dysplasia: A chronic lung disease in newborns, often defined by a characteristic appearance of the lungs on X-ray and the need for mechanical ventilation for more than 4 weeks.

Case management: Coordination and oversight of the package of services provided to an individual. Case management may be provided by an insurer, a pediatrician, a parent, a social worker, or some other health care professional. The comprehensiveness of case management, and its goals, depend on the manager.

Cerebral palsy: A paralysis of varying severity that results from nonprogressive damage to the brain at or around birth.

Copayment: In insurance, a form of cost-sharing whereby the insured pays a specific amount at the point of services use (e.g., $10 per visit). See also Coinsurance.

Congenital: Present at birth. Congenital anomalies usually refer to birth defects that result from imperfect development during pregnancy.

Cystic Fibrosis: An inherited disorder caused by the production of a unique glycoprotein that results in abnormal mucous secretions. It is usually fatal before age 20. Death is due to excess mucus in the lungs and to pancreatic insufficiency.

Deductible: The amount of health care charges that an insured person must pay each year before he or she is eligible for coverage.

End stage renal disease: Chronic renal failure that occurs when an individual irreversibly loses a sufficient amount of kidney function so that life cannot be sustained without treatment.

Chronic renal dialysis, kidney transplant surgery, and continuous ambulatory peritoneral dialysis are forms of therapy.

Gastrostomy: A surgical opening into the stomach. A gastrostomy tube allows food to be introduced directly to the stomach, bypassing the mouth and throat. A jejunostomy tube (which connects with the top of the large intestine) may also perform this function.

Hemophilia: A hereditary bleeding disorder distinguished by a deficiency of one or more blood coagulation factors-e.g., Factor VIII (hemophilia A) or Factor IX (hemophilia B).

Home health care: Medical and related services provided in the home.

Hospice care: Medical care rendered to terminally ill patients that is intended to be palliative rather than curative.

Incidence: The frequency of new occurrences of a condition within a defined time period, usually 1 year. Compare prevalence.

International Classification of Disease, 9th Revision, Clinical Modification (ICD-9CM): A two-part system of coding patient medical information used in abstracting systems and for classifying patients into DRGs for Medicare. The first part is a comprehensive list of diseases with corresponding codes compatible with the World Health Organization's list of disease codes. The second part contains procedure codes, independent of the disease codes.

Intravenous therapies: Nutrients, medications, or other treatments administered directly into the bloodstream (specifically, into a vein).

Long-term care: Health care of prolonged or indefinite duration. Long-term care hospitals usually have an average length of stay of 30 days or more.

Meconium aspiration: The existence of meconium, a dark substance normally found in the intestine of a full-term fetus, in the airway. Meconium aspiration can cause difficulties in breathing after birth.

Medical device: Any instrument, apparatus, or similar or related article that is intended to prevent, diagnose, mitigate, or treat disease or to affect the structure or function of the body.

Medical technology: The drugs, devices, and medical and surgical procedures used in medical care, and the organizational and support systems within which such care is provided.

Multiple sclerosis: A progressive, crippling disease of unknown cause that destroys the myelin sheath that insulates nerve cell axons. This results in slowed nerve condition. Symptoms commonly include weakness, lack of coordination, and speech and visual disturbances.

Muscular dystrophy: A group of inherited neuromuscular diseases that result in the progressive deterioration of muscle function.

Neonatology: The medical specialty of newborn care.

Parenteral nutrition: The intake of nutrients directly into the bloodstream (intravenously), circumventing the digestive tract. Strictly speaking, intramuscular administration of nutrients is also parenteral nutrition, but the term as normally used in health care implies bloodstream administration.

Patent ductus arteriosus: Imcomplete closing of a fetal blood vessel that allows blood that is low in oxygen to be returned to the body rather than to the lungs.

Phototherapy: The treatment of diseases, such as jaundice in newborns, with light.

Prevalence: In epidemiology, the number of cases of disease, infected persons, or persons with disabilities or some other condition, present at a particular time and in relation to the size of the population. Also called ''prevalence rate.'' Compare incidence.

Private duty nursing: Services provided by a professional nurse to a patient who needs individual and continuous care beyond the level normally provided by a visiting nurse (in the home) or the nursing staff (of a hospital or skilled nursing facility).

Pulmonary surfactant: A substance present in the lungs that aids in oxygen absorption.

Quadriplegia: Paralysis of all four limbs.

Respite care: Care provided in order to give family caregivers some relief. Respite care is a broad category that can include occasional home nursing or custodial care or institutional care.

Sequelae: Aftereffects or secondary consequences.

Shift nursing: Nursing provided in the home in hourly shifts (usually 8-hour shifts), as distinguished from nursing provided in visits (usually of an hour or less). See also private duty nursing.

Skilled nursing care: In this technical memorandum, any care that requires highly technical nursing skills, including care provided by nonprofessionals such as parents trained in such skills.

Spina bifida: A birth defect of unknown cause that results in incomplete or improper development of the spine, usually associated with the protrusion of the spinal cord through the bony spine.

Suctioning: As it applies to children with breathing difficulties, suctioning is the removal of secretions from the airway and is particularly important when the child has a tracheostomy tube (artificial airway) that could be blocked by these secretions.

Surfactant: See pulmonary surfactant.

*Task Force Definition of Technology-Dependent Child: ''A technology-dependent child: Is a person through 21 years of age; has a chronic disability; requires the routine use of a particular medical device to compensate for the loss of use of a life sustaining body function; and requires daily ongoing care or monitoring by trained personnel.''

Third-party payment: Payment by a private insurer or government program to a medical provider for care given to a patient.

Trachea: The airway extending from the back of the mouth and nose to the bronchial tubes (which lead to the lungs).

Tracheastomy: A surgical opening into the trachea. A tracheastomy tube is an artificial airway (a tube in the trachea) that opens to the outside at the tracheostomy, where it can be connected to a mechanical ventilator.

Urinary catheterization: The introduction of a tube into the urinary tract to withdraw urine.

Ventilator: A mechanical device used to assist in or control respiration by delivering an appropriate volume of gas to the airways or by promoting inspiration. In this report, it refers to both positive- and negative pressure devices that cause or help a person to breathe.

GLOSSARY OF ACRONYMS

AAP - The American Academy of Pediatrics.
AARD - American Association of Respiratory Care.
ACCH - Association for the Care of Children's Health.
ARC - National Association for Retarded Citizens.
ASPEN - American Society for Parenteral and Enteral Nutrition.
BMCHRD - The Bureau of Maternal and Child Health and Resource Development.
CAAP - Collaboration Among Parents and Professionals
CCS - Crippled Children's Service.
CHAMPUS - Civilian Health and Medical Program of the Uniformed Services.
CITP - Chronic Illness Teaching Program.
DOD - Department of Defense.
EPSDT - Early, Periodic, Screening, Diagnosis and Treatment.

*Task Force on Technology-Dependent Children definition.

FMAP - State Medicaid Assistance Percentage.
GAO - U.S. General Accounting Office.
HMO'S - Health Maintenance Organizations.
HHS - Department of Health and Human Services.
NICHD - National Institute of Child Health and Human Development.
NICHCY - National Information Center for Handicapped Children and Youth.
NIMH - National Institute of Mental Health.
NIS - National Information System for Health Related Services.
OHD - Office of Human Development Services.
OTA - Office of Technology-Assessment.
PFTH - Program for the Handicapped.
PPEC - Prescribed Pediatric Extended Care.
REACH - Rural Efforts to Assist Children at Home.
SPRANS - Special Projects of Regional and National Significance.

APPENDIX E

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